FINAL

An Independent Evaluation of the Nova Scotia Community Based Options Community Residential Service System

January 29, 2001

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For the Nova Scotia Department of Community Services

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Terms of Reference For The Review of The Community Based Options (CBO) Program of The Nova Scotia Department of Community Services

The Department of Community Services in the spring of 2000 engaged Dr. Michael J. Kendrick to evaluate the system of residential services entitled "community based options." This review was to be completed by the early autumn of 2000. The CBO system principally supports persons with either a history of use of psychiatric services or persons with disabilities of a physical or intellectual nature. The populations being assisted are typically persons with persistent and significant physical and mental impairments requiring some manner of ongoing assistance.

The following constitutes the formal terms of reference of the evaluation,

Given the limitations of government's/agencies and the state of the art; the independent review will assess if the current delivery of services to clients funded by the Department of Community Services in Community Based Options meets the needs of those clients. The review will:

- Examine and report on the current service delivery framework for clients funded by the Department of Community Services who require residential services in Community Based Options
- Assess whether the current model of service delivered to clients in Community Based Options offers the best chance to meet the needs of the client
- Drawing on the best practices of other jurisdictions recommend components of those services which could be usefully incorporated into policy in Nova Scotia

☐ Provide comment on whether the current "Interim Standards" which apply to Community Based Options should be incorporated into regulations

A report of the review findings will be made to the Minister of Community Services and subsequently released to the public.

Methodology Summary

The review "on site" component consisted of three visits to the Province by the reviewer. In the first, it involved meetings with the Department of Community Services, major advocacy organizations, and CBO providers. The second and third visits involved visits to communities throughout Nova Scotia including Sydney, Whycogomagh, New Glasgow, Antigonish, Truro, Halifax, Bridgewater, Yarmouth, Church Point, Kentville, and Wolfville. These "visits" included public meetings, visits with services, service users, families, providers, professionals, civil servants, and advocates.

A priority was placed on providing to consumers and families the most convenient and confidential means possible to obtain access to the reviewer. This included the opportunity to contact the reviewer anonymously or otherwise via email, by mail, or via a no cost "1-800" number. The review was advertised widely by public letter. The letter indicated the willingness of the reviewer to receive submissions and organize meetings with any interested group. Many submissions were received from individuals and groups on a wide variety of concerns related to both the CBO system and other matters affecting the lives of people served by this (sub) system. Almost all the groups and individuals seeking a session with the reviewer were successful in obtaining this. The reviewer also examined many dozens of documents related to the CBO system.

The report was developed in several stages, with the reviewer eventually submitting a draft to the Department of Community Services in late October 2000 for input, checking for accuracy, cross checking with the terms of reference and minor editorial matters. This was followed by a quite extensive final edit by the evaluator and submitted to the Minister in late December 2000 for the final check of details and public release.

Some Brief Observations On The Terms of Reference and The Evaluations of Systems

Terminology

There are many terms that are in use in both the mental health and disability fields that refer to the person that takes advantage of services that may be available. For instance, terms are used such as consumer, client, patient, participant and so forth. The reviewer will utilize the term "service user" throughout this report to refer to service recipients. This is not a reflection on the worth of other terms as the intention is to come up with a term that is broadly recognizable and unambiguous. The term "natural supporters" or "allies" is used to describe the many variations of unpaid supporters a given person may have in their life. Often this refers to family but certainly may include many other persons involved in the person's life. Also, when it comes to referring to the type of disability the person may have, the reviewer has chosen to use the general terms "impairment" or "disability" as an inclusive term covering all of the persons eligible for services. In reality, people live with all sorts of disabilities and of varying degrees of significance and thus defy easy typification. Given the uniqueness of each person, it is fitting that all general terms end up being inadequate in describing people.

The CBO System

This review was not intended as a review of particular agencies, sites, or services but rather an evaluation of the overall system of care and support encompassed by the term "Community Based Options ("CBO")." The CBO system has been in place for some time as a distinct "system" within the broader set of residential options covered under the Homes for Special Care Act. These other options include adult residential centers, regional rehabilitation centers, group homes, developmental homes, community residences, etc. "Small Options" homes i.e. (CBOs), are typically for three or less persons and rest in the category of unlicensed settings. The CBO "system" was not designed as such but rather grew into existence by increments rather than by some overall design.

Since the CBO system is so directly linked to the Homes for Special Care Act, and the arrangements it has had in place for a quarter century, it is somewhat artificial to view the CBO system as operating entirely in isolation. It is now, in terms of size, the largest portion of what might be thought of as the entire or overall residential service system for these populations. From the vantage point of the ordinary service user, the CBO sub-system is the most plentiful of the major community residential options they are potentially eligible for, and thus must be assessed as to its advantages and disadvantages *relative to other possible residential options*. The Department of Community Services has recognized this hugely important "relevance to the needs of service users" question in its terms of reference.

The evaluation, therefore, has been undertaken with a view to examining the CBO sub-system from the vantage point of its relevance to meeting needs of its present and, by implication, possibly *future* users. The essential evaluation question and focus has been service user well-being and best interests, as per the Department's instructions.

This has been subsequently taken up on three distinct levels. The first is observations on the CBO "model of care" itself, and its pros and cons. The second is observations on the formal overall encompassing system of the Department of Community Services, broadly shaped in its origins by the Homes for Special Care Act. The third is the even larger "system" of the service users and their families and other allies who participate in and rely on this system, the interested and engaged public, the community service providers, the Department (and other government departments and other regularly involved parties. This latter "system" extends beyond the more narrow confines of legislated or regulatory arrangements, to the actual operational functionality of this residential system as it occurs in daily practice in the everyday day course of home and community life.

The Department of Community Services, to its credit, has quite consciously opened its system to independent to critical examination; particularly in reference to its question about the "best practices" that ought to be adopted in Nova Scotia. This decision may prove to be enormously timely, as it may enable Nova Scotia to position itself for future progress by properly taking stock of what improvements are feasible and desirable. It is clear that such a sensible precautionary "look forward" has been neglected in many other jurisdictions, and it may well be the case that Nova Scotia's decision to "get out ahead of change" will leave it better positioned in the years ahead. A lot will depend on the way the inevitable challenges that are involved with progress are taken up.

The overall "system", comprised of service users, families, providers, and the Department of Community Services (and the Nova Scotia Department of Health), ought not to be seen as unrelated to each other as each interacts with and is interdependent on the other. The overall well-being of the people served depends enormously on the human, moral, and intellectual investments made to keep this system properly in balance. The needs of people are only partially met by formal services, in any case, as so much of what is good in life comes through life sharing with ordinary people in the community. Thus if the "needs" of people are to be central to the evaluation of the CBO then the relationship of the CBO system to the broader community, especially at the personal involvements and relationship level, emerges as an important dimension for examination.

This also requires due attention to matters such as values, leaders, "voluntary" involvements in people's lives, work force development, supports for innovation, and other concerns pertinent to the net result of quality services and supports. Operational effectiveness ought not to be confused with simple administrative expedience. True (programmatic) effectiveness is much more tied to the proper relationship of costs to ultimate benefit (cost-benefit balance). The production of benefit(s) to service users requires that the proper supports be in place for the person. It also requires that suitable relationships and attitudes be in place in regard to various key participants such as service users, families, providers, advocates, and civil servants.

For these preceding reasons the review will not just examine the CBO system as it currently is constituted, *but will look beyond its present configuration to what it might someday evolve towards.* Naturally, the wisdom and timing of pursuing any of the recommendations contained in this review, rests principally with the Minister of Community Services and the government of the day. *All reviews are ultimately advisory in nature and constitute only one element of the overall considerations that must come to bear regarding public policy.*

A critical distinction needs to be made between a study of the views of the many participants in the system and an evaluation of the system itself. This is an evaluation of the CBO system and is therefore an appraisal of the system *by the evaluator.* The evaluator was extremely eager to have people influence the evaluation and was able to be quite comprehensive in enabling this to occur. *Nevertheless, in the end, the evaluation is not a survey of opinion of the people in the system, but rather a summary of the evaluator's professional assessment of the particular strengths, weaknesses and future challenges of the CBO system.* Consequently, it should not be confused with a polling of the populace, as much as this function was prominent as an influence on the evaluator. The evaluator has undertaken this appraisal based on some core assumptions and principles against which the CBO system has been measured. These are stated very briefly here but are greatly expanded upon in the narrative of this report.

- In judging the worth of a service system the best measure is the extent to which it benefits the lives of the people it supports.

- If a system impedes the practical progress that is possible in the lives of individuals, then that system may be working against such person's best interests even if this is unintended

- The quality of a service will be greatly enhanced if the needs and interests of the service recipient are positioned to be the dominant influence on the service design and operation

- Service users, their families and other close personal supporters should be recognized as being an authority on their own lives and this should not be displaced or devalued by the way services actually operate

- In any system that is involved in the long-term care of individuals, there is always a danger of fixing that care into routine patterns of custodial conduct.

- Custodial care must be balanced by an emphasis on the forward development and growth of the individual, and this advancement should not be held hostage to the convenience and preference of the system of care.

- The goal of community living for persons with impairments should not be fixed for all time in the patterns that were originally possible at the time of the initial phasing down of institutions.

- Good quality community living should involve efforts at improving the role of people within community and the challenging of practices that hold people back from what is possible for them.

- Good quality community living is not ultimately solely or fundamentally about the kind of care or support people receive in the community, but rather about the kinds of lives they ultimately get to live within community.

- It is only possible to assure quality in community living when the practice of community living fully involves people in creating satisfying lives for themselves within the community.

- Diverse and fulfilling lives for individuals throughout the community cannot happen without stimulating all sorts of formal and informal partnerships and collaborative roles with all elements of the community.

- Leadership for improvements in community living must come from the huge grass roots base of the community where most lives are lead, and this “engine” of community acceptance and dynamism is the core target of any viable “community living enhancement” strategy.

- Professionals, advocates, governments, service providers and others associated with the formal system of supporting people, are key catalysts in advancing the fate of community living whenever they mobilize the citizenry to welcome and enrich the lives of their fellow citizens who live with impairments.

- Most enactments of significant community change will happen fundamentally a person at a time i.e. small changes are the seeds of big ones

- Investing in people helps enable them to learn, change and be part of the transforming of community, even if this is one person at a time.

- As people are alerted, motivated and educated to change and advancement, they are proportionately more able to pursue improvements of significance.

Much, if not most community and service leadership, can come from interested, involved and committed individuals from the "bottom up", if this is foreseen and welcomed. The mobilization of these masses of people is intimately tied to what is perceived as being possible to achieve in both services and people's lives. Community living is not the same as obtaining a community service, as the latter should be a servant of the former.

A Brief Description of the (CBO) "Small Option" Model of Personal Residential Support

The CBO "model" does not represent an entirely "fixed" model of support, as there is a degree of variation of these living arrangements. Nevertheless, it would be accurate to say that, in general, they constitute households involving three or less persons with enduring physical or mental impairments, who are believed to require staff or other support at various times while they are at home. Not all residents have formerly lived in institutions but many have. The homes rely on either shift work staff or live-in staff or a combination of these.

The "CBO" homes are operated outside of government licensing under "interim standards" of the Nova Scotia Department of Community Services. The operators are largely "non-profit" organizations, though a small percentage of the operators are "for profit" businesses or municipally operated Adult Residential Centers. It is notable that virtually none of the CBO homes in Nova Scotia operates under the direct control of service users or their families even though many of these came into existence due to their activism. Persons entering such homes do require classification by the Nova Scotia Department of Community Services, and their "per diem" rate must be approved by the Department if they receive public funding. Such rates vary from home to home and can vary even within homes. The buildings are either owned, rented or leased by the supporting agencies or businesses. Service users do not typically own their own homes *at this point in time*. Staffing is widely available on a shift work model though many other variations also occur. Though there is a possibility of confusion *in* the nomenclature of the Nova Scotia Department of Community Services for its residential service options, these (CBO) homes would in most other jurisdictions be considered small group homes, supervised or supported apartments, adult shared living and some form of adult family care.

Some Initial Cautions About Generalizing Across Home Support Situations That Involve 1700 or More Individuals

It should be obvious that while the many CBO homes resemble each other in most respects, there still remain variations across the individuals and homes that is both appropriate and expected. Even within homes "operated" by the same agency, one can easily distinguish quite different "personalities" for each home that derive from the people involved in the home, the staff called to support them, the "culture" of the agency and so forth. Nevertheless, it is also recognizable that the "modus operandi" of these homes is patterned sufficient for comparison and contrast with other possible patterns.

The Organization Of This Report

This report has been organized in three broad sections apart from the introductory elements covered thus far. The first concerns the evaluator's assessments of the major strengths of the CBO system. The second concerns the evaluator's observations on problematic deficiencies in the CBO system and includes the major recommendations of the evaluation. These are broken into seven broad categories. These categories are further divided into two sub-components. The first is observations and comments on particular problems. This is followed at the finish of these by recommendations and numerous subsidiary recommendations. The third section of the report deals with the comparative situation of the CBO system relative to other jurisdictions, a brief section regarding the limits of individualized support options and some concluding remarks.

The Small Options (CBO) Model and System: Some Programmatic Observations On Its Strengths

Overall Observations And Comments

The CBO sub-system of the Department of Community Services has proven itself to have many advantages. These advantages are sufficient in scope and quantity that it is probable that the CBO model of supports will continue in use in Nova Scotia for some time yet, as part of a "core" pattern of support for persons living with long-term mental or physical disabilities. It is likely, however, that the CBO model will gradually diminish in importance as other more personalized support arrangements (PSA's) are developed on a more widespread basis. While it would be inaccurate to describe the CBO model of support as "dated", it is fair to describe it as being increasingly eclipsed by more "person-centered" approaches to residential supports that are now in practice in Nova Scotia and elsewhere in the world. Nonetheless, in its own terms, it is a "robust" combination of models that could readily manage most of the fundamentals of supporting the majority of the people requiring services within the community. This has already been seen. It also represents a considerable improvement on earlier models, particularly of the congregate care variety.

Some Advantages of the (CBO) "Small Options" Model of Personal Support in the Community

Observations and Comments: The CBO Model Does Provide A Well Demonstrated Alternative To Institutional Living

This pattern of support has been used in Nova Scotia and elsewhere, for over a quarter century, to assist individuals to leave residential institutions successfully on a permanent basis. It would be virtually unheard of for individuals thus relocated to ever again need long stay institutional care. In this way, it demonstrates the viability of community care, at least insofar as re-institutionalization is not required.

It is notable that the Department of Community Services that by 2000 the number of people in Nova Scotia residential institutions has declined from 1200 in 1985 to slightly more than half as much. This trend is consistent with international patterns. For instance, within the United States the number of residents of institutions has declined, (on an overall national averaged basis), by approximately 1.5 % per annum steadily for decades as established by Braddock et al. This statistic, however, does not capture the effective rate of institution phase down that is possible in states that have turned their minds to creating an entirely community-based system. In many such states, the institutions have been completely eliminated (e.g. New Hampshire, New Mexico, Vermont, Rhode Island etc.,), or as is the case in larger states where this process has been compounded by size, the rates are still well beyond this e.g. Wisconsin, Pennsylvania, Massachusetts, Michigan etc.

A large number of the people who have come into the CBO system may have at one time or another spent years in the institutional care system and thus represent as difficult a population to serve as can be expected in any community service system. Their needs are highly variable and range from individuals whose requirements for support are incidental and transitory to persons who may be receiving twenty-four hour a day care. It is notable that these individuals are routinely supported within the CBO system.

This is not the same as claiming that this "model" or patterns of support uniformly provides high quality community living for all those assisted. Rather, it permits the reliable maintenance in the community of a wide array of persons who were either formerly resident in institutions or who entered service directly from the community. Beyond simply being physically in communities, it has helped many with developing elements of their various personal lifestyles in the community. Their success as individuals with the challenges and opportunities of community living, (from within a CBO arrangement of support), varies widely. Their "success" with community living is often taken to be simply that they do not return to institutions. After an initial transition period, this criterion gradually becomes increasingly irrelevant as they settle into their new life in the community.

Observations and Comments: Many Examples of Personal Progress With Physical and Social Integration Into The More Obvious Aspects of Life In The Community.

The lives of the many people assisted within the CBO sub-system easily discredit the many doubters of past periods, who questioned their ability to adjust to community life. It is also true that a similar disservice has been historically rendered to the broader community, in the assertion of claims that predicted the widespread rejection of significantly disabled persons by communities. None of this has come to pass beyond some initial uneasiness, and Nova Scotians have proven themselves as accepting of the presence amongst them of persons with significant and often very evident impairments. This same positive result has been seen everywhere in the world where this move has been attempted. It seemingly always begins with alarm and ends quietly in the unobtrusive and often unheralded progress of people's lives.

Time and time again, the stories of people's lives in the community are replete with instances of admirable community conduct by both the persons with impairments themselves and the broader community. These positive instances have become so common by the end of the century that they quite rightly are seen as "unremarkable." Nevertheless, such quiet progress ought not be ignored, as it clearly points to a process of ongoing and, (thus far), increasing social acceptance of people whom society has in the past excluded and mistreated. In many notable instances, persons with seemingly entrenched reputations for poor, inappropriate or even harmful personal conduct have shown, after many years of considerate support, to be capable of quite different and positive patterns of behavior. Such persons had, in the past, provided justification for the existence of institutions. *It is all the more important that it now be seen that we were very wrong to be so pessimistic in the past about such persons and that, if we remain open, their future potential may yet surprise us, given the right conditions of personal support.*

Nova Scotia had once been a pioneer in providing community supports to the most significantly disabled persons as far back as the early 1970's with the closure of the Mountain View institution in Kings County. At the time, this institution had the most highly dependent and disabled residents that one would find anywhere. The subsequent successful relocation of many of them to communities throughout Nova Scotia, was many years ahead of what was being attempted at the time in most jurisdictions. In Canada the only comparable attempts to do the same with as significantly disabled persons did not occur until the 1980's with the exception of Newfoundland which quickly followed Nova Scotia's example with its children's institutions beginning in the 1970's. In the 1980's this was seen more extensively in Alberta's services for dependent adults, the closure of institutions for the medically involved in British Columbia and the Roberts Hospital School in New Brunswick. This innovative and visionary "edge" still exists in some practices in Nova Scotia. However, its present rates of closure of institutions and the return of residents to communities are now well behind many other leading jurisdictions such as much of New England that achieved "institution free" status by the early 1990's. Nevertheless, it is important to see that this capacity to innovate is present, in both a latent and expressed form in Nova Scotia, *providing there is sufficient community-wide leadership present to catalyze this capacity and a supportive attitude by the government of the day.*

It would be incorrect to conclude, despite these many positive examples not withstanding, that Nova Scotians who live with significant impairments are generally well included in community life. This difficulty mirrors the pattern throughout the western societies of persons with disabilities struggling very hard for a valued place in the world. Many people struggle to find valued roles for themselves within community life, and a substantial majority still have lives of persistent social isolation. While these difficult conditions are common throughout many western societies, it is important to note that overall trends have improved in the right directions over the past several decades. This is to be welcomed. The challenge of maintaining this trend will be taken up later in this report. Nevertheless, credit needs to be given for the location of the majority of homes well within communities rather than in remote, isolated locations. A key strategy of doing this has been the CBO system.

Observations and Comments: Utilization of Normative Community (e.g. Ordinary Homes) Housing: Minimal Use of Purpose Built Housing

The CBO System could be characterized by its lack of reliance on special "purpose built" housing for persons with impairments. Instead the reliance has been on utilizing "ordinary homes on ordinary streets", thereby permitting the residents the customary anonymity that typical housing affords its occupants. This has the advantage of reinforcing a positive image of the residents as being in their rightful place within community. "Purpose built" homes often have the disadvantage of being only for a stigmatized group thereby setting them apart. This practice of using ordinary homes seems due not so much to formal government policy as it is a result of the recognition of its merits at the level of practice.

This is not an argument against the specialized adaptations of ordinary homes to accommodate the needs of persons with physical impairments. On the contrary, it is highly useful for there to be a greater range of choices of places to live for persons who will need physically adapted homes in order to be able to function adequately. Rather, the intention is to not create homes that are unnecessarily stigmatized by being readily identifiable as being for a socially disadvantaged group.

This concern to make available the wide choices of "ordinary" homes to persons with disabilities applies to all of the internal and external elements of homes. Every effort should be made for the home to be like other (typical) homes notwithstanding the individual tastes of those whose home it is. In the best arrangements, appropriately physically adapted ordinary homes would meet all three of the key criteria of being functional, aesthetic, and non-stigmatizing. Much of this sensitivity was evident in the CBO system though there were areas that could be strengthened.

Observations and Comments: Stability and Dependability of Personal Support Within Community Care

In a public atmosphere wherein vulnerable people are perceived by many people to have been "dumped" from institutions unsupported into the community only to be neglected and abandoned on the streets, it would be tempting to raise alarm by saying such practices are widespread. This would unmistakably be a gross distortion of the actual facts of the situation. Despite this evaluator looking explicitly for a pattern such as this, *not a single party came forward to the evaluator with evidence of this nor did the evaluator discover such a pattern through his own investigations. As such, there is no evidence of any kind that would support the proposition that there might be in Nova Scotia an explicit or covert policy of throwing people out of safe environments in favor of diminished governmental fiscal responsibility for their care.* Nor is there credible evidence that this same end is being achieved unintentionally through professional or governmental mismanagement of a systematic sort.

The much stronger evidence is that the government of Nova Scotia is not being systematically neglectful of such persons within the terms of albeit increasingly dated service models and practices. Its lacks as a government over the recent decade have been more in the "letting go" of this area of public responsibility as a priority for leadership, innovation and forward progress. There has not been some sort of crass and cynical abdication of its responsibilities for those it has accepted to support. Though countless people expressed to the reviewer their deep suspicions of the motives and preoccupations of the permanent (bureaucratic) government in particular, none argued that the government was actually involved in or tolerant of the abandonment and neglect of people it had taken responsibility to care for.

A more legitimate criticism of governmental policy would be that this and previous governments have frequently acted to limit governmental responsibility by refusing to fund an expansion of service. This policy has undoubtedly contributed to the widespread view that government cannot be trusted to "do the right thing." This failing is quite different from that of relieving government fiscal pressure by "offloading" people in services to be cared for on an unfunded basis. It is undoubtedly correct, however, that government has been hugely neglectful of family support as the "core" element of a desirable community support system. There will be more said on this later in this report. The important point to make at this juncture is to recognize that the Province of Nova Scotia has entirely honored its commitment to the dependable continuity of care that would be expected once people are accepted into service.

Observations and Comments: The CBO System Has The Capacity To Alter Spending To Reflect Individual Variation In Needs

It is not uncommon in many residential services system that the funding levels are fixed by generalized "across the board" formula that result in standardized levels of payment. Not uncommonly, these systems utilize some manner of system of funding "tiers" or levels. Individuals are assigned to the level that ostensibly meets their needs. This is not the case with the CBO sub-system, in that funding levels can, in theory, vary according to personal need. Consequently, funding levels are not uniform and, in fact, are negotiated on a person-by-person basis.

It is a common preoccupation of some forms of bureaucratic mentalities that "equity" in the system can be achieved by giving to each service user the exact same pattern of service and spending as is given to another. Equality is believed by such persons to be achieved by uniformity and standardization. This approach is flawed on several levels. First, it ignores the reality that the needs of individuals are not uniform, even where people have the same diagnosis. Secondly, the standardization of rates eliminates the need to "personalize" supports, i.e., to tailor supports to actual needs rather than to calculate need based on abstract categories or labels. Third, standardization imposes unhelpful, rigid "fixing" of costs, thereby prohibiting the flexibility necessary for thoughtful and targeted economization.

The CBO sub-system has managed to avoid these pitfalls, and thereby has preserved *the hugely valuable advantage of being able to respond to individual difference*. This advantage is greatly diminished by the tendency to assign individuals in the same home the same rate of payment in a kind of "de facto" averaging of costs. It is nonetheless commendable that the funder has occasionally negotiated directly with service users and their families as a response to *their* perceptions of what is needed and wanted. This bestows upon these persons the very important role of being considered, (at least modestly), by the authorities as being authors of their own lives and supports.

The criticism that there is no "rhyme or reason" to the rates being paid is a legitimate one, insofar as there does not presently exist a sufficiently transparent set of governmental principles, criteria, and considerations to be balanced in terms of funding awards. This measure would not, by itself, alleviate the suspicion for the deeply mistrustful that there is indefensible inequities in how funding has been allocated. Still, it would move such a discussion to a fuller and richer sense of what are legitimate elements of costing that need to be individually balanced for services targeted to individuals.

The CBO system does not have a recognized and usually "standardized" system for budget negotiations at this individual level. This is advantageous in not adding another layer of rigid bureaucracy, but it leaves a vacuum, at the level of routine processes, as to specifying how and when individuals served and/or their families and advocates might engage the funder on such matters. This element will be taken up later in this report.

It is widely recognized that the CBO system has some of the highest per diem rates of any residential service option. It is also true that these high rates are by no means evenly distributed. It is to be expected that some individuals will have costs associated with their support that are highly unusual and expensive by comparison with others. This kind of comparison is natural and often very illuminating. However, there is a danger that (expected) instances of poor funder judgment, (almost a "given" in most systems of adjudicating needs), might serve to constitute a rationale for imposing uniform funding levels. Uniform or "set" levels tend to mindlessly substitute the necessity for careful individual judgments as to what people need by using abstract and prescriptive mathematical funding formulas. The CBO system *is to be credited for its willingness to let individual needs trump preexistent bureaucratic formulas. This results in the dominance of the principle that funding can vary according to individual need.* Such a principle is hugely important administratively in justifying why the system must bend towards individuals rather than the reverse.

Observations and Comments: The CBO System Permits A Measure of Relative Personalization of Resident Groupings

One of the great disadvantages of institutional and mini-institutional residential services is their tendency as settings towards "mass" living, i.e., where the needs of the group dominate individual needs, preferences, and priorities. In fact, it is a common observation these days in Nova Scotia and elsewhere, that many established community based residential services have developed a kind of institutional flavor to them. Various factors can contribute to this "mini-institutional" culture including the size of groupings, the extent and character of staff presence, attitudes, and routine, etc.

The CBO system has not escaped these pressures whatsoever, but the extent of these has been significantly minimized by the rigorous restriction of resident groupings to three residents or less. There are few states or provinces where such a fidelity to the reliance on small settings has been systematically pursued. This parameter, of no more than three people having to live together, has been hugely difficult to sustain as an upper limit for congregating people within one setting. Nevertheless, it is a limit that ought to be held in almost all instances. The further one gets away from the forced grouping of residents, the less one hears the criticism of mini-institutional culture. However, even in an instance where only one person is served in a setting and, notwithstanding that this person might be resident with non-clients, there is still a danger that such a person may become "institutionalized within the community."

The resolution of this problem is greatly helped by smallish groupings and, therefore, *the CBO size restriction is an extremely important advantage that ought to be maintained as a maximum target level for resident groupings.* Nevertheless, this measure alone cannot properly address the larger pressures towards "mini-institutional" culture. It has to be seen as, at best, a rough guideline for only one element of a thoughtful counter-custodialism strategy. This matter will be taken up more fully at a later point. The maximum size of three is one of the most compelling features of the CBO system, and is very much in line with size restrictions in many other localities that have moved to assure residents more individualization and to minimize "mini-institutionalization". There are still jurisdictions in the world that would envy this feature as they are saddled with far too many large group residences. Nova Scotia has these but not in the CBO system.

The term "permits" in regards to the "relative personalization" of people's homes is chosen to reflect the fact that it is a helpful, but not sufficient element, of helping residents have a "real home." The other elements of what is needed in this regard will be taken up elsewhere in this report. However, it should be noted that it is still quite rare in actuality for residents within the CBO system to be meaningfully involved in controlling who gets to live, work, and even visit their homes thereby voiding much of the advantage that is brought by small groupings.

Observations and Comments: The CBO System Technically Permits (But Does Not Normally Assure) Meaningful User/Family Involvement, Management, and Governance of Service

The average CBO home is largely controlled on day-by-day matters by the provider organization involved. This applies to the design, management, and governance of service. In fact, there is little doubt as to whose home such homes really are, i.e., they are in essence the homes of the provider. This is not meant to suggest that residents and families might not be involved in decisions around many matters, but this is more likely to be a consequence of their own personal actions than primarily due to the system itself. As such, the usual provider management system is not currently designed to achieve empowered service user/family involvement though it does not explicitly prohibit it.

It is revealing that while there are highly credible examples in Nova Scotia of both individualized self-management and collective governance of residential services, these sorts of options are very rare *on an overall comparative basis.* More common in practice are instances of receptivity by both providers and funders in regards to the particular expressed wishes of the more active service users and their families. This kind of occasional role for consumers and families is largely one of their *advisory and episodic* involvement. By "advisory" it is meant that the funder or provider seeks input and advice but does not actually share or promise to share control and authority over how services actually operate.

Even with this significant limitation in mind, it is important to recognize that everyday responsiveness to service users and their families is desirable in itself and ought to be commended. In almost all instances where services were praised by service users and families, it included this sense of responsiveness. It also points towards a hunger amongst such service users and families for what may be termed an honorable and respectful relationship between services and those they assist. This desirable feature of "right relationship", as a key element of service quality, was present in the CBO system despite the lack of formal empowered roles for service users and families.

It might well have been true that greater dissatisfaction with the relatively disempowered status of service users and families in the CBO system, might have been expressed if the system had promulgated such an expectation over enough years to shift perception towards seeing this as a "realistic" expectation. As it stands at present, most service users, families, advocates, providers, and funders are so (collectively) inexperienced with anything other than traditional advice-giving roles for consumers and families, that it is quite predictable that most would settle for very little in this regard. This is less likely once these same people gain practical familiarity with more empowered arrangements around the design and operation of support arrangements.

Observations and Comments: A Degree of Genuine "Personalization" of Homes

There was evidence everywhere that many of the ordinary people in the CBO system had been able to achieve a quite extensive degree of "personalization" of their homes. By this term "personalization", it is meant that the resident's personality, interests and preferences were taken into account in the aesthetics, routines, attitudes, decorations, and other aspects of the atmosphere of the home. In this way the home tends to reflect the identity of the people that live there.

It should be noted that such "personalization" represents a continuum from a few modest measures to rather extensive efforts to ensure that such a home is a "real home" for the residents. Much of this had appeared to occur more as a function of the values and sensitivities of the people involved, as there was scant evidence of any formal recognition of the this element of creating a "real home" as a key factor in service quality. Nevertheless, these effects are a very welcome sign of the desire of many individuals to extend to persons with significant disabilities the kind of recognition of their overall needs as human beings to have their personhood respected. It is a good example of how the beliefs and attitudes of the many people involved create "policy through practice" more than that policy "comes down" from the authorities. To be fair, the authorities would largely favor a policy of "homes being real homes" though they have little in place to encourage this beyond the policy in favor of small settings.

The creating of a "real home" is in contrast to simply creating a place to live. Though it may strike many people as strange, it is actually quite possible for individuals to have shelter but not actually have a "home" in any customary sense of what this means to most people. It is an important step towards recognizing the full humanity of people to see that their needs as a person extend well beyond simply being safe, having shelter, and regular meals. The fact that so many people can grasp this point of "real home" calls into question instances where it is overlooked or ignored. Still, the many ways in which people with disabilities have been extended the identity of being "people just like all other people" has been widely demonstrated in the CBO system and provides a very positive basis for future strategies to go even further.

Observations and Comments: A Measure of Local Community Oversight, Influence, and Involvement With Service Providers

It is important to note that virtually all CBO home support arrangements are theoretically under a degree of oversight and influence from and by local communities. This principally has legal effect, since almost all providers are nominally under the direction of community boards. It is much less true that community involvement has been as prominently emphasized over the long term as it had been in the founding years of many agencies. In this way, what had started as community based grass roots concerns, usually highly linked to the lives of the people served, has become overshadowed and displaced over time by a very "agency centered" style of operation. By this it is meant, that the home and the lives of the people in it, may often lose focus as more everyday managerial matters assert themselves as an operational necessity.

Such a pattern is widespread in the field, not just in Nova Scotia but much more broadly. Therefore, it is all the more satisfying to continue to see the presence and involvement of people whose interests are largely personal and voluntary in the lives and well-being of residents. In many instances, this has been expressed via organizational roles such as board members, volunteers and the like, but also is seen in people being casual friends and advocates for the residents. One would expect families to be involved, and it is often enough true that agencies go to some lengths to assure that this happens. In the case of some agencies, supporting various forms of this voluntary "community" involvement in the lives of the residents is the cornerstone of their ethic and history as an organization.

In many instances, it is clear that the senior staff properly serve at the pleasure of their boards. Still, many people feel that community board oversight and local community involvement are being gradually displaced by the control of the day-to-day operational personnel. It is difficult to precisely assess the full extent to which agencies have lost or recaptured authentic local community oversight and influence. It is also dangerous to make too much of the very limited number of community and relationship involvements actually experienced by residents. Nevertheless, it is still important to recognize that these do exist, even if under the increasingly inhospitable conditions of managerial rather than citizen control of agencies. These positive examples offer both hope and practical insights for their greater proliferation should there be concentrated efforts to nurture these in the future.

Observations and Comments: Examples of CBO Arrangements That Permit Some Versions of Adult Home Sharing With Non-Disabled Persons

Though the "average" CBO largely operates as a household of "clients", often supported by rotating shift workers who do not live in the home, there are instances where living arrangements involve people who share the home *as their own home*. These "home-sharers" are themselves not persons with a disability though some are paid to provide some staff like functions. The more conventional "mini-group home" arrangements largely operate on the assumption that people with impairments ought to, or need to, live solely with other recipients of service. In reality, this has become an unthinking habit in the way services have been set up. i.e. "formulaic" service design. That this is not a necessity can be seen in the examples of instances where people with disabilities choose to live with non-disabled persons and vice versa. Nevertheless, people are much too quick to rule out the possibility that persons with disabilities and other ordinary citizens could and would share lives and homes were this option readily supported.

The importance of these examples is not simply to dissuade those who have relied entirely on congregate care models to see that there are alternatives. It also helps to point out that people who live with significant impairments can very much participate in the wide array of living arrangements available to all citizens. Once this point is clearly understood, it becomes far less "necessary" to involuntarily group residents with people with whom all that they share is a common "clienthood". Equally, it brings the attention more properly on the establishment of households based on the shared needs and specific identities of the actual residents, wherein such co-residents could potentially include the whole of the broader community. This further underlines and supports the need for persons who live with impairments to be seen as more fully like all other people in the community. Therefore, practices that do not require their sequestering into "special" places to live, reserved apart from others, are quite practical and needed.

Observations and Comments: Pioneering of Service Flexibility And Avoidance of The Currently (Institutionally Derived) Classification System

The CBO system heralds an important initial step forward from a residential system that "fits" people to categories of service rather than designing services to fit the needs of people. It does this by right of making suitability for a CBO service to be, in effect, simply a matter of eligibility and priority. In this way, the CBO sub-system has pioneered some key fundamentals of a potentially much broader future system to personalize the support options people may need on an individual basis.

The fundamentals are that the crucial role of funders, and other key service designers, is not to limit the residential options available to individuals to an unnecessarily limited menu. Rather, its task is to use available resources, *as flexibly as possible*, to permit any number of variations of support arrangements (i.e., personalized support arrangements) that may be feasible within whatever budget is available. The logic of the Homes for Special Care Act echoes the institutional thinking of the system of classification of individuals that was pioneered and implemented in the last century in prisons, mental hospitals, developmental disability institutions, and aged care long-term care settings. The key assumption of such systems was to find the most suitable institution, (or a part thereof), for the person. These classification based systems still exist today. They require that there be in place standardized categories of service models, such that a person can be adjudicated as being more suitable, (and eligible), for one than another. The driving force behind many of these may not actually be the need of the person but rather the need of the system *to locate the most affordable of its currently available options* for the person. This search for affordability is not, in itself, a difficulty, but rather the problem is with *its unwitting reliance only on available options.*

What the present CBO system illustrates is that government can play a quite constructive role in fostering flexibility in service design, by making the key entry requirements to service become eligibility and priority, and by dropping the use of the "personal suitability to an existing residential option" premise of the current classification system. The fact that most providers still have simply gone on to create quite conventional service models, is much more a question of insufficient orientation and exposure to other more flexible options. Like everyone else, including service users and their families, there has been little sense that one could "think outside the box" and simply use existing funds more creatively and flexibly. Yet, this has occurred in enough instances under the CBO system, to reinforce the premise that it could occur yet more widely. This would require that government was itself more clear on the aim of making available more personalized and flexible support options. There is no doubt that this direction is practical and desirable if done well. It is therefore important to appreciate what has already been established and achieved *within the existing CBO system* and how *this can be capitalized on in future stages of development.*

It is useful to recognize that the current dominance of home ownership and tenancy arrangements being near exclusively in the hands of providers and for-profit businesses, could readily give way to many more arrangements where both service users and/or their families might hold such control. This would require the establishment of possibilities like this being included on a long list of possible options that could be negotiated on a person-by-person basis as these may make sense for given individuals. It is not a matter of whether everyone would seek these particular features, so much as those that wanted to could pursue them within the bounds of eligibility and priority for funding.

Another illustration of the value of flexible service models or arrangements can be seen in the case of service or support arrangements organized to take into account other important variables of personal preference that may have a bearing on residential choices and supports. These would include cultural, ethnic, religious, linguistic, and even dietary needs and preferences as core components of a household. While the population of Nova Scotia is not as diverse in scale as many other parts of Canada, it does nevertheless have its share of individuals for whom their unique cultural needs may be a deciding factor in the kind of home life that would be most optimal for them. To some extent, this has been recognized by the CBO system but would be greatly expanded were the CBO system to reach even further in its fostering of flexible and personalized support arrangements.

Observations and Comments: The Development In Nova Scotia of Community Service Provider Capacity To Manage Small Options Homes

It is useful to recognize that, as a kind of "infrastructure", that the provider "system" now in existence in Nova Scotia constitutes an asset that has been built up over several decades, to the point where they now constitute the backbone of the community system of support. At one point several decades ago, the municipal or provincial government run services, e.g., RRC's, ARC's, CTC's, etc., had provided much of the available residential service management capacity, albeit of institutional models of service. With the passage of time up to the present, this prior system has declined to the point where the community system is now the dominant one in terms of size. This is significant from many viewpoints, but certainly there needs to be an appreciation of the crucial role community providers are being asked to provide in the delivery of supports to often highly vulnerable persons. They are now the "backbone" of the present system, and what they are able to do or not do will define this emergent systems character.

This community agency management capacity has grown gradually in much the same way that the governmental role direct institutional service delivery has declined. It is significant that the government of Nova Scotia has not itself entered into direct community service delivery. They have thereby avoided the many ways in which governmental bureaucratic culture can spill into the home lives of people when the government is the direct operator of people's homes.

The growth of the network of community agencies has meant that, at least in theory, the culture, value, and methodologies of providers can vary to reflect the founding vision of that particular agency. In Nova Scotia, in the CBO system, this has meant that those who want service have, in principle, available to them considerable variation in agency competency, philosophy, and practice to choose from. Despite this "theoretical" advantage it is noteworthy that "placement" in the CBO system is still routinely more driven by what is available (i.e., vacancies) than by service user choice. Nevertheless, there is clearly diversity in the capacities of community agencies, including various degrees of "specialization" regarding the kind of support they offer. This is an unexploited asset if viewed with service user options and choice as a benchmark. Nevertheless, if what the providers offer is too narrow or standardized then this potential advantage dissolves.

What should not be missed in this pattern is that, if this amount of variation can be achieved in a system that relies heavily on standardized service models, then an even greater diversity of provider capacity can be expected once the goal of personalized and flexible support arrangements is given greater prominence. Nevertheless, community provider capacity is often quite highly linked to the vision of what is offered or sought by funders. For this reason, the eventual resolve of government to move towards a strategy of more flexible personalized support arrangements will undoubtedly prove decisive as to what the service user will eventually be able to look forward to.

Observations and Comments: The Evident Shared Passion, Interest, And Commitment of Many Service Users, Families, Providers, Civil Servants, And Advocates

The evaluator was very impressed by the large turnouts everywhere in the Province for public sessions concerning the CBO review. Also impressive were the many groups that sent submissions and letters or arranged special meetings. This outpouring of concern often began with the expression of their many fears and misgivings about the perceived limited availability of the current community supports system. These were frequently accompanied by expressions that could only be described as a deep sense of despair about the future for those awaiting access. In other instances, the quality and rigidity of the services came in for criticism. The bulk of this was occasionally directed at the politicians, but more frequently at the senior bureaucratic or "permanent government" of the Department of Community Services and, in particular, the head office of the

Department of Community Services. Nevertheless, criticisms were common enough about particular providers though these tended to be offered in private.

The actual content of this despair, and the strikingly low lack of trust and credibility, often directed at the senior levels of the government bureaucracy, will be taken up separately in this report. What needs to be pointed out here was a widely prevalent feature underlying this more overt expression of malaise. This was an unrelenting curiosity and hope for a better future for people living with mental health and disability-related difficulties that was encountered everywhere in the Province. There was a palpable hunger for a better vision for the future, and the leadership that might be required to achieve it. This anticipation is not particularly farfetched as it is largely consistent with where the overall field is at this time. The community service field has evolved rapidly in the last three decades, and what is now possible to look forward to can be measurably better than what was common even a decade ago. The advances in practice have come rapidly, and many informed people were concerned that the CBO system was not now reflecting this atmosphere of forward movement.

Those coming forward were eager to see these types of advances, (largely what might be called "person centered" residential options), apply to Nova Scotia and the lives of the many people they were personally concerned with. In a very direct sense, many expressed the view that they placed much hope on this evaluation to act as a catalyst or symbol for change. Though this particular hope seems somewhat misplaced, it does nevertheless underscore that there exists in Nova Scotia a very large base of concerned people who are very willing to work for a better future. Further, the better informed increasingly view the present system as having become unnecessarily "stuck" in the visions of prior periods and were very eager for some manner of "leap forward."

Their despair at the absence of sufficient leadership and forward momentum, was often directed at the government bureaucracy and its apparent longstanding failure to formulate a way forward. Though on one level this provided an unconvincing bogeyman for all that ailed the system, on another level it also constituted an inverted expression of the hope for something better that sat beneath the surface negativism. It was almost a kind of plea for progress. The Department of Community Services was for many the most prominent place to start complaining about, but the real dissatisfaction was more diffuse, and reflected a sense that the needs of many people were not well enough attended to. The underlying hope this reflected was, in another way, a kind of faith and conviction that there was much that could be possible, if the way forward was opened up. This hope was certainly disguised and hidden behind the more obvious disenchantment with the perceived "stuckness" or immobility of the overall system in recent years. The selective attribution of the cause of this decline solely to the senior bureaucracy, has elements in it of a much broader blaming reflex directed towards government to solve all manner of societies difficulties. Nonetheless, it clearly constitutes an implicit offer to government, (and to each other), to strike some sort of vitally needed and updated partnership for progress. However, the possible shape that this partnership could take remained very opaque for most people.

What should not be overlooked is that there is still a widespread and possibly expandable constituency of hope in Nova Scotia for a better future for people who live with various significant impairments. While this constituency is now clearly depressed, discouraged, and searching for direction, it is clearly also true that a reservoir of goodwill and energy exists in the community that can be mobilized, expanded and focused for good. Providing that this "community concern and commitment" is seen as the "asset" of human capital that it is, then a lot of the complaining of the moment would quickly disappear once a positive strategy existed to direct this will into avenues of progress. Often when progress is made, it turns out that the most crucial resources that were mobilized were not financial but rather human ones. With proper and supportive strategies of "people building" in place, this asset of a committed base of community concern and enthusiasm for change and challenge will undoubtedly become even more valuable. The Department of Community Services, for its part, certainly can do much to turn this situation around if it wanted to, and the challenge will be to develop the updated strategies that can build the needed forward momentum.

Still, this is impossible without a kind of grand alliance with the community and this must be again fashioned for the challenges of a new era.

It should also not be overlooked that the overall priorities of the Province undoubtedly, (and appropriately), limit and shape the range of action of individual government departments. While the public face of the Province is more likely to be, on a day-to-day basis, the more permanent government departments and their officials, it is still the political leaders who have the final say. Thus, it is important to not overlook this factor even when the public may fail to mention it.

Observations and Comments: The Capacity of The CBO System To Respond To Quite Diverse and Specialized Needs; Even Innovatively In Some Instances

The CBO system serves a wide variety of individuals, many of who were, at one time, challenging to properly support in community settings. Nevertheless, this system has demonstrated that even these more "difficult-to-serve" individuals can be dependably supported in community settings. This includes people with multi-disabilities, people with persistent conduct disorders, persons with a need for substantial supervision, people with significant communication impairments, persons with difficult to define disorders, persons with intensely anti-social conduct and so forth. All of these persons are currently served in community settings, notwithstanding the many problems their care and support demand. Such an outcome would not have been seen as being credible, even several decades ago, and it is a testimony to the ingenuity, commitment, and good judgment of the many countless individuals involved with the CBO system that has contributed to such a result.

This is not intended to mean that, in each instance, that such individuals are optimally being served, but rather that, considerations of quality aside, the task of people being served is being managed within the CBO system sufficiently well to conclude that it largely "works" as a core residential option. It also clearly does not mean that the CBO system couldn't be evolved to become a better system in terms of outcomes for people. Rather, the point to be taken is that it has been a largely functional system for supporting people. This has been found to be true with small options systems worldwide providing they are managed responsibly and with good attitudes.

The more crucial question for the future is working out how to make available to Nova Scotians the next generation of ways of supporting people in the community. This can begin with building from the benefits that have come with conventional CBO support arrangements. A crucial foundation for this purpose is clearly the ways in which the CBO system has had the flexibility to adapt the supports in people's homes, so that the widely divergent needs of the many people served can be responded to as uniquely as can be managed given the providers way of doing things. This is much more possible in the CBO arrangements than in the larger groupings that had preceded these. At the same time, there are limits to what the CBO arrangements can offer, and this creates room for the system to evolve. Whether the present CBO system will actually evolve in keeping with the lives of the people, will depend on whether what has already proven to be feasible, at the programmatic level, is expanded upon or ignored. Without some conscious focus on adapting the CBO system to the innovations that are now possible, then the people currently being supported will be deprived of what might otherwise have been to their advantage. The key to build upon is the hard work already done in the CBO system to see each individual as unique, and to develop arrangements that go beyond the CBO stage in meeting people's needs. As has been indicated already, there is ample reason to believe that there are many talented Nova Scotians ready to participate in innovative change, if this is repeatedly encouraged by those in authority and those proposing change.

Observations and Comments: The Emergence of A Measure of Local/Regional Self Sufficiency In Terms of Support Options

Though it would be hugely overstating the case to say that there exists sufficient numbers and types of personalized support arrangements in every region, the basis for such increasingly comprehensive regional systems to play a larger role in the future, is becoming more apparent. There are several elements to this already in place. First, there now exists the provider and governmental capacity in each region to plan, fund, operate, and oversee local personalized support arrangements. This does not mean this cannot be expanded to meet greater unmet needs, but rather that the initial basis for obtaining support options is locally /regionally present. This is much less clear in the mental health case.

Secondly, the Department of Community Services now has, and has technically had for some years, the legal and financial mechanisms in place that would permit the regional decentralization of virtually all of the substantial decisions affecting services. It is true that these are not currently organized to the point where they could be used to systematically implement a decentralized regional support service system. In fact, as a matter of structure, these are still in their infancy. Nevertheless, there has been a broad "in principle" recognition, within the Department, of the possibility and even desirability of moves in this direction across many service areas.

What is missing are explicit mandates and mechanisms that would permit substantial community direction and governance of the regional system, as well as more detailed means by which local people can organize to address gaps in support, opportunities to innovate, and ways to safeguard people and quality at a regional/local level. It is also true that this Department has had very little recent experience in sharing authority, control, and leadership with the community and vice-versa. Nevertheless, these are normal enough developmental problems, and could be relieved as obstacles within a short matter of time if decisions were taken to resolve today's ambiguities.

The importance of appropriate decentralization of services, resources, and decision-making close to where people live cannot be underestimated. It means for service users and families, the ability to get the help they need, *near at hand*, in their local community rather than relying on a system that favors those people located in more populous locations. It also means that there is less likelihood that ordinary citizens will have to spend endless frustrating hours trying to find someone in remote hierarchies that admits to having the authority to take responsibility for unsolved matters. Consequently, it permits local needs to be largely solved locally, and thus leaves ordinary people with a system that is all that more "people friendly". Admittedly, much lies ahead to get such arrangements in place, but it is important to recognize what is already in place, and how this can be the seed of what could come.

Some Key Observations On The Limits And Problems Associated With The CBO Model and System

Section One: The Need For Political Leadership and The Modernizing And Renewal Of The CBO System

Observations and Comments: Lack Of Political Priority On The CBO System: Stagnation and Lack Of Progress

The many service users, families and professionals who approached the evaluator varied extensively as to their judgments about the CBO system. Many were simply grateful to have a service, and were most anxious about whether what they had could be "taken back". For them, the immediate problem with the system was whether service would be dependably there for them in the future. They were very distrustful of the motives of government and quite clearly were anxious that cutbacks would leave them stranded. For many service users, the proposed moves, (more apparent than real), to "claw back" social assistance were very unsettling. For individuals and families who did not have access to services at the moment, the same fear of government being unwilling to provide support was at work. This anxiety added a note of desperation and despair about the future. In such an atmosphere of trying to either obtain or hold onto services, it was often difficult to get people to see the system with any sense of reflective analysis, since so much of their best energies were tied up with what might be thought of as basic "survival" issues.

However, once this issue was eventually gotten to, it was clear that many of them had never really thought very much about what was actually possible for the system to become. This included many of the professionals as well, since for many of them the best of their energies were going to simply gain access services for people. People had developed such low expectations of the system itself that they hadn't ever really given much thought to its improvement. Consequently, many had confined themselves, quite pragmatically, to simply trying to eke out some minor advantages "here and there", as opportunities arose. In a very real sense, many had now so little faith or expectation in the system that they had actually "given up" on it. In fact, the evaluator was constantly asked whether there was any point in them "raising their hopes" about the system. Many people were highly suspicious of the evaluation itself as they worried that it was some scheme by government to further reduce spending. Many said quite directly that their expectations were very low as to what the CBO system might be able offer.

This attitude of "survival" reflected a quite realistic sense that the various governments of the day had not placed priority on this system for at least a decade or more. The consequence of this neglect was a gradual dissipation of the momentum of the system and, in particular, a long period of not being able to "look forward". This is not meant to say that no progress whatsoever had taken place, but rather that the CBO system had become a kind of "poor cousin" in terms of both political and departmental priority. As a consequence, the dynamism of the system had become quite depleted.

It was very difficult initially for the evaluator to establish that the evaluation was indeed interested in what "best practice was". Many were incredulous that the Department of Community Services had actually asked for input on this as a key part of the evaluation. Many people wanted to know whether the Department was at all sincere in its interest in the subject of quality and service. Though this question could not be answered, having it aired made it possible to gradually move onto the questions of a more programmatic nature concerning the CBO system. It was at this point that it became clear that many people were, or had become, very vague about what was actually now possible in the field by way of residential supports. Such was the rarity with which questions of progress had been aired as a practical public prospect.

As the subject broadened, and as people heard and discussed more aspects of it, it became very clear that they were nevertheless very interested in having their vision of what might be possible expanded, and in exploring the various challenges that this might include. It became gradually evident that, once the immediate issues of service access were put aside, there existed underneath a considerable interest in what might be done to improve the options for people in Nova Scotia.

At the same time, the fact that many of these people had spent, or been encouraged to spend, so little time on such matters, gave the evaluator a strong sense of the extent to which people, (and thus the system), had become preoccupied solely with service expansion and access issues. Similarly, it was clear how little energy had, comparatively, been put into what might be thought of as "people and vision development". It is highly doubtful that this was a "planned" strategy of the authorities, so much as it reflected the pragmatic focus on more elemental gatekeeper matters. At its root, this may well have been motivated by the Department's appropriate concern to not (unfairly) create expectations in people for options that the Department had inadequate resources to fulfill.

Whatever the origins, the long-term effect on people, within and outside the system, had been a general dampening of expectation that the system could or should improve, *in its own terms,* thereby leaving only the questions of getting or keeping services. The obvious drawback in this was that a sizable number of service users, families and professionals had not invested very much energy into thinking ahead. Most, in practice, had not thought much about what the next steps forward with the CBO system might look like. Despite this limitation, people everywhere seemed eager to explore the issue and were particularly interested, as had been many people in the Department, in getting a sense of what "best practice" might be, and what others in the field were doing.

It was obvious that questions of this sort had not come up for many of them all that often. The exception to this largely involved a smaller portion of more extensively involved civil servants, service providers and advocates who had clearly examined these questions more extensively and who more closely followed external trends. Many of these individuals had thought ahead to what the implications of a shift in vision might entail. Nevertheless, even with these persons, there was a sense that matters were "on hold" and that little could be gained by expanding one's vision given the lack of movement in the system.

It is notable that in locations where progress is witnessed, that it has usually been preceded by a period in which people have investigated or been exposed to many ideas and possibilities that challenged their thinking and expectations. This process of exploration, investigation and debate typically serves as a kind of "stage setter" for the eventual activism and program change that results. It seemed probable that this developmental stimulation had been lacking in recent years in Nova Scotia, and partly accounted for the slowdown in evolution and improvement of the CBO system. This effect of lowered expectations seemed more than simply a resigned reaction to governmental spending restraints, as it also seemed linked to a paucity of opportunities occurring more widely to raise consciousness, engage interest and generally stimulate vision. It is therefore not surprising that innovation in the CBO system had been similarly restrained. This regrettable diminishment seemed to be directly related to people's opportunity to be exposed to progressive possibilities.

Observations and Comments: The Combined Government And Voluntary Agency/Advocacy Sector Appears Collectively Depleted

It is evident that the advocacy movements which have historically been the engine of change and advancement of Nova Scotia's community service system and, in particular, the CBO system, are now showing predictable signs of fatigue. This is not unique to Nova Scotia, but rather reflects the aging of the post war and "baby-boom" founders and leaders of many advocacy and voluntary organizations. The long-term strain of having lobbied and struggled for decades to build support for the "cause" has taken its inevitable toll after these many years of activism. This is most evident in these organizations becoming preoccupied with the ongoing operational responsibilities of now well established services, the low formation rate of new innovative organizations, the difficulty attracting a new generation of dissidents and leaders, the lack of investments and resources directed to the future and the general fatigue of present day leaders.

This description, while general in nature, naturally has many exceptions to it. Nevertheless, the gradual transformation of the "baby-boom" activist social movements into established and even "institutionalized" service providing organizations, has resulted in a perceptively slowed down pace of change and development in the last decade. Services and spending have continued a modest expansion, but it is almost all in models of service that had been pioneered in the 1970's. The CBO system is the clearest expression of this. The pace of innovation relative to the CBO system and its possible evolution into a next generation system of services is very low, at least as can be witnessed in the formation of distinctly new concepts and practices.

Part of the difficulty seen in other jurisdictions, and apparently also true for Nova Scotia, is that service provision roles, (by voluntary organizations), typically deplete and mute the kind of intense advocacy that propel established bodies such as governments to undertake change. The absence of the kind of high risk taking, but also passionate and visionary advocacy, typically serves to set the stage for the authorities to settle into a kind of "stall", until the next wave of change overtakes them. In Nova Scotia, there does not seem to have been the kind of strength of investment in fresh people and vision to muster the kind of dynamism that it takes to move governments and other "institutionalized" and established interests. This pattern is very comparable to what one sees broadly in Canada and elsewhere in this period. Thus, it is always worthwhile to look for instances that countervail against this trend.

This kind of "social movement" decline can occur, even when there are still strong membership bases for these voluntary organizations, if they loose their appetite or internal support for the kind of activism that can often be internally and externally divisive. Yet, ironically it was this kind of activism that fomented the moral, political and ideological constituencies that were the social movement bases for what became the present CBO system. Thus, it did not seem all that surprising that the CBO system was itself showing signs of fatigue and need for renewal.

Governments can be highly responsive to the demands that emanate from deeply concerned citizens who are willing to put their convictions and commitments to the test. The presence of unrelenting pressure and public profile of people and groups, willing to take their case for justice or change to the public, has underpinned the ability of governments to obtain the needed priority and will to make the kinds of advances that were needed. The CBO system has risen from this kind of stimulus, and now languishes in a lower state of priority and momentum due to its weakening and even decline. This diminishment is necessarily cyclical, as the toll of years of building for a better future is not inconsiderable. However, if there is not the necessary "counter investments", the depletion and decline can remain entrenched and even worsen.

The critical consequence is the effect of a loss of dynamism outside of government on the ability of governments and the voluntary sector to create, together as a united synergy, the conditions by which advances are introduced to the field. Like any catalytic energy, the "spark" of unrest, rising hopes and expectations and a vision for something better is absolutely a precursor for change. Stimulating this to happen is certainly bound to disturb the status quo, but with the compensating advantage of encouraging creativity. With such ferment will come many of the raw ideas that form the same sort of breakthroughs as did the CBO's in their infancy. With its absence will come the "freezing" into place of the patterns of today and the stalling of progress.

Observations and Comments: The Need For The "Next Generation" of More Individualized Service "Models" For The CBO System

The various individuals and groups that approached the evaluator varied considerably in their sense of what the system might need. Many had proposals that reflected an emphasis on making the system more accountable by strengthening the bureaucratic policing of the services, while others emphasized increased funding or perhaps improved standards. Many of these notions did not converge particularly well, as could be expected with any cross section of opinion. Nevertheless, where they did almost universally agree was in their sense that the CBO system wasn't well enough developed to respond to the complex needs of individuals. Though many were unsure of how this might be remedied, there was largely a consensus on the need to improve the system in regard to the individualization or "personalization" of services and supports. This was also the view of the evaluator.

As has been indicated, the CBO system, as presently constituted, is able to support the vast amount of people needing service with a certain measure of dependability. However, this is different from whether the CBO models, as currently configured, are either optimal or desirable on an individual basis. They still hugely rely on group solutions that insert people into "pre-cooked" arrangements rather than "tailor-made" ones. Where such "personalization" of service does occur, the effects on individuals is naturally better. The CBO models of the moment unnecessarily place limits on what is possible for individuals. This tendency is much less prominent and problematic in what many call more "person centered" approaches. It is these sorts of options that the CBO system is not generating in large numbers, nor can it do so without a major new generation of programmatic strategies suitable for this purpose.

The reason for this lack is readily apparent. The CBO system has relied disproportionately on what might be thought of as shift work oriented "mini"-group homes. While these options may continue to have a place for some time in any future CBO successor system established in Nova Scotia, their current status as a disproportionately dominant model deprives service users of much that would benefit them from other strategies of organizing services. In particular, it is clear that *personalized and flexible community support arrangements* are programmatically and fiscally possible, *even within much of the present system as it is now constituted.* In fact, they already exist in the CBO system. When discussed publicly, there appeared to be much interest in the Province towards exploring how these options might be made more available. Nevertheless, as indicated before, many people were skeptical that the Department of Community Services or most providers shared this interest. Nevertheless, underneath this initial skepticism existed a great deal of curiosity and a desire to engage the challenge. Clearly, there is much discussion and exploration ahead as to what is practical and it is encouraging to see this interest.

What has emerged as a defining or pivotal programmatic issue is the unnecessary narrowness of what the present CBO model(s) normally permit in practice. As indicated already, the "theoretical" possibilities of the CBO system are not being developed to their potential. This results in service users, providers and others with an interest, from not being able to as easily produce outcomes for the service user that are as extensively personalized as is feasible. The CBO system effectively does produce somewhat standardized residential sites, but does not presently provide the flexibility to produce the variability in supports that would permit more extensive and comprehensive individualization. It is interesting, nevertheless, that at least some agencies have had success along these lines, and that *where there are now a few, there could some day be many.*

The present lack of momentum towards personalized support arrangements derives from factors originating from many quarters. It is true that when it comes to building towards a key decision of some kind to resolve this issue, the responsibility to do so will initially fall quite expectedly on the involved politicians and senior civil service. Notwithstanding this crucial starting point, the probable success of any possible initiative to improve the CBO system *over the long run*, will rest on the more widespread ability of people closer to the grass roots to be able to experiment with ways of achieving this. Consequently, what the broad field in Nova Scotia does by way of stimulating and testing its thinking, through a proliferation of small "next generation" projects that embody an ethic of increased personalization, will inevitably prove to be very influential in what is possible for the present CBO system to gradually achieve.

This question of creating flexible personalized support arrangements is clearly one that is highly linked to the CBO system's ability to foster innovation in conjunction with the individual concerned. This is because, in principle, all individuals are unique, and so might be the pattern(s) of their support. The present CBO settings are highly standardized by comparison with this potential. Many of the major innovation related implications, for the system as a whole, will be taken up later in this report. Nevertheless, the CBO system could become more flexible in responding to individuals, if there was a specific provision or capacity to intentionally and incrementally create more diverse individualized arrangements of support. This is currently missing. The responsive support options that do already exist allow service users and their families to meaningfully shape the way support is given. *However, these do not result from any such specific intention or program in the system itself*. Instead this has largely arisen from local initiative. To its credit, the system has casually accommodated these instances, but principally in their status as anomalies. More will be said momentarily on this aspect of things. Informally, a few people may be occasionally able to "bend the rules" and thereby help make exceptions to the pattern. Still, even the need to do this points out that the formal system itself is a problem. The CBO system has largely been a system to deliver largely "fixed" or standardized rather than variable programmatic "products". Seen in this light, it cannot help but be an impediment to those seeking outcomes that are crafted or delivered in a possibly unique or non-uniform manner. What needs to occur is simply that this purpose be the basis of a specific new set of mechanisms to assist people.

While this shortcoming has been attributed here to the overall CBO system, it very much will have to involve the future joint conduct of advocates, providers and the civil service at the level of implementation. There now appears to be a widespread interest in improving the options available to the people served, so this historical shortcoming *does not appear to be due to some measure of opposition to the idea itself.* Its prevalence suggests that people either may not know how to achieve these sorts of results, or they are stymied when they do so, or both. In any case, having a specific intentional systems capacity to create such options will undoubtedly help to move matters along. After all, such mechanisms are routine in many jurisdictions, and it would not take much work to have this option available in Nova Scotia. Nonetheless, this is a decision that has yet to be taken by Cabinet and resolutely executed the Department of Community Services.

If one considers how such diverse jurisdictions such as Newfoundland, California, New Hampshire, Massachusetts, Alberta, Wisconsin, Western Australia, Queensland, Australia, Hutt, New Zealand, Glasgow, Scotland and others manage to have available good examples of service "personalization", even within broader parts of their overall systems that do not follow this same line, it generally is very dependent on the authorities proving to be very flexible in regards to individual service users and their supporters attempting arrangements that are anomalous. It is even more highly dependent on the presence of local "leaders" and innovators who are able to create just enough "space" or "running room" to "bend" the system so it fits individuals better. Their ability to "shape" into existence something that had not existed beforehand is the essence of making these types of arrangements practical

There are many aspects of this "amount and quality of 'personalized' residential options" question that will be taken up throughout this report. It is important to recognize that these matters tend to be highly interrelated with the question of innovative leadership and are best seen as being so. It is also unwise and not practically possible to narrowly isolate the CBO system from the larger system within which it operates, as they are highly intertwined. Even small changes in the CBO system would act to spur on developments that don't presently occur because they are not explicitly being sought. It is also important at the outset to note *that the evaluator sees the problems, with the* *present CBO system, to be largely "solvable" matters provided that there is competent leadership exercised* ***jointly*** *by advocates, the authorities and providers toward this end.* It is true that this would take some time, but the eventual outcome seems realistic if the intentions are firm. It is also important to see that such progress would very quickly follow if the Province itself called for changes of this kind.

Observations and Comments: Widespread Discouragement And Demoralization

It was immediately obvious to this evaluator, almost from the very beginning of contact with the many people associated with the CBO system and, in particular, the service users and their families, that people were hugely frustrated with the immovability of the current CBO system and the apparent futility of their efforts to move it to improve. This was apart from their other worries about simply gaining access to services. This concern had, at its roots, the frustration about how one would go about influencing things for the better. The perceived lack of their success in doing so had left many bewildered and pessimistic about the future. There was virtually no confidence expressed that the authorities would ever "do the right thing for the right reason". Even the evaluation itself was initially seen as suspicious, with many people quite clearly believing that there had to be some perverse motivation behind its commissioning. This premise, of course, created predictable puzzlement as to why an independent international evaluator, widely known for being progress minded, had been selected for the task.

This disaffection with government is hardly unique, as there are all too many ways in which governments provide a very useful scapegoat for any number of grievances. It is not even that the disenchantment with the senior bureaucracy, and to a lesser degree the ever-changing politicians, is all that unusual. What made this despair more worrisome, was the desperation underlying the belief that that there was no way to go forward in the official system. People repeatedly expressed a view that had elements of anger, frustration and bewilderment.

It took quite some time, as has been indicated earlier in this report, for the evaluator to see that behind this complaining was actually a plea for hope. It was not that people were ultimately hopeless about the *inherent* prospects for people who live with significant impairments. In fact, the attitudes of ordinary people in Nova Scotia towards a better life for people with disabilities were quite fair-minded and largely hopeful. Rather, they were reacting to the fact that the system had not, at either the official or practical level, offered any directions or signs of forward direction that would be recognized as being decisively and persuasively hopeful. The unrelieved freeze on CBO spending was merely another bit of evidence that this general view was justified. It was also true that the Department of Community Service had been stalled for many years in being able to offer a positive forward program. Whatever efforts they had made internally to this end were not at all known or visible to most external observers.

The specific psychology underneath this particular despair is useful to note and analyze, as all despairs may not be equal. In this instance, the root of this despair was in the perceived stagnation or lack of forward momentum of the system. It might have been expected that the lack of prospects for new spending would have emerged as the more central focus, yet this was rarely mentioned. The appetite for signs of (official) hopeful forward progress, and the absence of many of these, was much more fundamental than any specific criticism of the formal system itself. In a direct sense, this underlying need for hope to be affirmed, represents a key leadership challenge in the immediate future. In another way, this hunger for progress was also expressed their dismay with themselves, in that they had been so unsuccessful in creating it through their own efforts. *Thus, while this frustration was directed at the authorities, a share of it was also directed at their own impotence to be able to move the system along in a forward direction. Hence, their intense demoralization and discouragement was due to their experience of frequent ineffectuality in regards to securing better futures for people.*

This experience of prolonged futility from being stymied, revealed a widespread desire on the part of many people, both inside and outside of the system, to (still) try to find ways in which they could act to make things better. It is very notable that this was not expressed as a desire for further participation in the present advisory structures of the authorities. Rather, it was a desire to be part of creating something new that they perceived would be more meaningful to the people's lives with whom they were involved. The despair that many people expressed was quite associated with the fact that many people did not feel it was "their system". Even though many were occasionally highly involved in various aspects of the system, many people felt disenfranchised from shaping it. Their voices were the alienated and seemingly powerless voices of people who saw themselves "on the outside looking in". It is not that surprising, given this outlook, for people to be so unwilling to take much responsibility for their own possible part in whatever was lacking. Still, they saw themselves *as very much wanting to be part of making progress and were still looking for how this might be possible.* They had not, in reality, given up hope, but very much needed reassurance that there was a realistic basis for hope.

It was the view of the evaluator that the presence of such a psychology was entirely understandable. There is indeed enough truth to the claim that the system is largely, though not wholly, programmatically stagnant. It is also true that the overall CBO system is virtually devoid of effective community partnership mechanisms and values, and other more personalized kinds of involvement arrangements that can result in ordinary people having a measure of useful influence. The view that the system was "other than theirs" was essentially correct. In fact, overall control of the CBO system, at this point in time, is still largely in the hands of the Department of Community Services head office, as the mechanisms needed to move this control "outwards and downwards" into the sphere of grass roots people remain to be convincingly developed.

This is a "systems structure" matter that derives from how authority is specifically apportioned under the current system arrangement. People have quite correctly seen this as an issue, but are far less clear about how this might be changed in a thoughtful, useful and ultimately empowering way. It is also true that the Department of Community Services has not recognized this officially as a problem at all, and so does not have anything specific by way of a public plan or proposal to settle the matter.

In fact, the present system structure has, in its essential elements, been largely unchanged for decades. There has indeed been some been occasional and modest service expansion within largely conventional service models, some ongoing and much needed institutional phase down, the recent absorption of the municipal programs into the Provincial system, and a variety of more recent administrative initiatives around standards, some much welcomed increases in salary levels for community workers and attempts to install minimum trainings for residential workers. As virtually everyone agreed, including many in the senior civil service itself, the system's improvement had long been in need of being a higher community and governmental priority. Few would outwardly disagree that it has needed renewal and modernization. Nevertheless, no plan or mandate to provide this exists, and people are not sure where to turn in this vacuum. Were such a plan to be sincerely explored and charted, it is likely that the present morale problem would shift remarkably. The perceived long-term lack of high-level political and bureaucratic decisiveness to move ahead has clearly taken its toll.

It is the view of the evaluator that while such pessimism is understandable, it now has come very close becoming an unproductive sense of defeat and resignation, that can actually reinforce the very apathy that it laments. The reality of governments and social movements is that one can never know for sure what might happen next, and it is always useful to continue "imagining better" even when the way forward is blocked for the moment. The psychology described here could change virtually overnight were there to be even a few fundamental decisions taken by Cabinet and the Department of Community Services, (hopefully in conjunction with the community's leaders), to renew and gradually modernize the system. Were something like that to happen, it would point out the value of having in place the necessary sound thinking about what progress could actually look like at the actual person-by-person program level. Ample enough energy has gone in recent years into maintaining the current system, rather than in properly imagining a better one. Consequently, when the chance for change does come, the changes actually then sought or advanced could prove more modest and disappointing than might otherwise have been true, had people been using this slow period to prepare the way forward. Still, this ground can be made up if the opportunity to come together is created.

Observations and Comments: No Effective Forward Planning For Dealing With The Future Needs Of People And The Wisdom Of Supporting Natural Supporters

Those who follow demographic, social and other public trends necessarily must look beyond the pressures of today, to what might be coming in the years ahead. It is not always possible, even with such forward planning, to always have available what is needed when the time comes. Nevertheless, it is wise to try to anticipate future need, and to begin whatever can be done to better position the system in question to deal with what might arise. In the case of the CBO system, the most likely events that will trigger a demand for services will be where individuals currently supported by their families can no longer be supported. These are currently "unfunded" individuals and thus are "outside" of the present CBO system. However, they largely fit the profile of the people presently served. It is clearly in the public interest that the Nova Scotia Department of Community Services be as prepared as it can be for the kinds of needs that will inevitably arise as these individuals and families find they can no longer manage.

What creates and "drives" a residential care system, under governmental authority, is the fact that governments usually have a public responsibility to not neglect the needs of vulnerable, dependent or significantly disadvantaged persons. The residential system is what is put in place to continue the care and support of individuals that cannot any longer be supported solely by their own efforts or by their "natural" supporters. Oddly enough, the core life-long system in society for the support of persons with disabilities, (of all ages), is not a governmental program but rather families, friends and other "natural" supporters. Residential care is merely a late-appearing component of the much larger and more fundamental system of ongoing "natural" and family support. It would therefore seem that the more astute forward planners would be those who work closely and proactively with families and other "natural" supporters. Their key task would be to help make it easier for these "natural" supporters so that they aren't forced to prematurely give up this task due to a lack of support. It would also be true that when the time comes when the family or natural supporters can no longer manage, the process of putting in place alternative supports needs to be timely, orderly and relevant.

It is a curious matter of timing, that at the very moment that the CBO system is being externally reviewed, the core direct family support system of the Department of Community Services is being transferred to another government Department. i.e. the Nova Scotia Department of Health. Since 1993 this program has been technically a legal responsibility of the Department of Health but the Department of Community Services has continued to have the day-to-day administration role. *This apportionment of responsibility of responsibility for home care for persons with disabilities and mental health involvements to the Department of Health seems an extremely imprudent action, given that this same direct family support system is the singularly most crucial tool currently available to the Department of Community Services to shape the future demands that will be placed on the residential care system.* It is also true that this would "structurally" encourage the Department to get out of touch with the very families and other supporters who provide the first line of support for people. This arrangement invites the kind of discordant schism that will lead to the government continuously being caught unprepared. It also now replicates the same kind of dysfunctional split jurisdiction that has so hampered the development of community supports for persons with mental health disorders.

It is important to make a key distinction as to what might be meant by the term "family" or "natural" supporters. In the case of children it is often, but not solely, their immediate or substitute family. Nevertheless, this may also include their extended family, interested friends and neighbors and others such as godparents. In the case of adults, those playing a "natural" supportive role may be even further afield including employers, colleagues and even acquaintances. Thus, in the casual use of the term "family support", it is actually meant families *and others in a natural support role*. This is not meant to mean that families are not as central when people become adults, as it is inevitable that adjustments in their role ought to occur to reflect the now more mature identity of the person. It is still true that family and people in family-like roles of support, are just as fundamental to people's well-being in adulthood, as they were in other periods of one's life.

It may not be well known that where there exists ample, flexible and family governed family support services, *the "demand" for conventional residential service is greatly lessened*. Also, it may not be immediately seen by many people that there is a considerable overlap between flexible and personalized family supports and good personalized "residential" support. The reason for this is that, whether people are currently living with their family or reside in another location, the key will be whether they are suitably supported. As such, it is rarely true that housing, (i.e. where one dwells,) is as ultimately crucial to one's life as how one is supported. Lifestyle support is what lingers beneath the surface, when only housing or placement matters get the attention. This is because "getting a life" is typically much more highly related to one's enduring needs and life satisfaction. *Hence, one may still not have much of a life even when one is adequately housed.*

Residential services are often seen as a panacea for needs that are not really residential needs. Thus the "residentializing" of people may actually not meet their needs. This is because the underlying personal needs of the individual are ignored or deferred, on the premise that *just getting a place to live will settle these matters*. What has to be further factored in is the question of the relevance of the (proposed) residential service to the person's key life needs apart from housing itself. This gets obscured when "bricks and mortar" are held up as the answer. Their very tangibility is seductive because, after all, houses are easier for many people to see and grasp, than are the more elusive questions of the well-being of a given person. In essence, simply placing people in a home may be all that many people think is necessary to meet needs. i.e. *residential placement gets treated as being equivalent to meeting the person's needs.*

The advantage in flexible personal and family supports is that resources can be targeted directly to the person's crucial needs. Further, there are more diverse configurations, combining both "natural" and paid supports, that are possible than is usually the case with "fixed" residential models. This ability to use resources more efficiently, than is the case with standardized residential settings, normally means that resources "find their mark" because of being better aligned to personal need. Keeping this rationale in mind, it is preferable to begin first with targeted personalized supports. The unnecessary "residentializing" of people, in this framework, represents a failure to find and support adequate personal supports. This does not make the use of residential services invalid, but rather places their use as a temporary or possibly long-term back up. This is in contrast to using them as the first line of attack on the question of supporting an individual. It is also important to recognize that placing people into controlled congregate residential settings is often done at the expense of responsiveness and flexibility, and locks the person and the funder into a long-term, if not perpetual pattern, of recurring residential costs. Over a lifetime, this is hugely costly and notoriously unsatisfactory, particularly if the person is custodialized.

What this logic leads to *is seeing that the "core" community service for people should not a residential one, but rather something more approaching flexible personal and family supports targeted on an individual basis.* This present distancing of personal and family support from the CBO system, locks Nova Scotia into a dominant and probably unsustainable reliance on expensive residential care as a solution to people's needs. Since a more flexible non-residential support option is not sufficiently in place, it is predictable that there will continue to be strained natural supporters, and intense unrelieved pressures on the residential system. Were flexible personal and family supports seen as the "primary" service, then residential care would diminish in importance and priority. The current system arrangements clearly invite people in need of support to now frame their needs as being best addressed by some kind of CBO, thereby accelerating (artificially) the "need" for CBO's. Were the same needs to be addressed by another set of arrangements then the utilization and "demand" for CBO's would conceivably diminish. It is important to recognize that even "fixed" residential supports can be converted back into flexible personal and family supports, if there are appropriate mechanisms for doing this. Much of what is now considered exemplary "person centered" service has come about from taking the resources used to "residentialize" someone, and freeing them up to be used in a different way. This kind of "unbundling" of resources ultimately means fewer resources in conventional residential services and more in flexible individualized support arrangements. This may well be worthwhile if, in fact, the more individualized resources are authentically targeted on people's needs due to their relevant use. The crucial question is whether the resources are well spent, and this can only be known on a person-by-person basis. Nevertheless, the more the support system takes account of the natural supporters and works with them (rather than apart from them), then the greater the chance that resources will be used productively.

Major and Subsidiary Recommendations Concerning The CBO System

The core recommendations of this report are organized as either major or subsidiary recommendations. The subsidiary recommendations generally fall within the major recommendations on a section-by –section basis.

Goal: To Renew And Modernize The CBO System and Return It To An Appropriate Level of Priority In Government

(1.0) Major Recommendation One: **The Province of Nova Scotia Should Authorize The Necessary Modernization and Renewal Of The CBO System**

The CBO system is a crucial system for the people of Nova Scotia and will be for years to come. In recent years it has been neglected in terms of the political priority and attention it has been given. It is very much in need of a timely updating and modernization. Such a major repositioning of the system has not occurred for several decades, and the neglect of this sort of *overall* renewal has left it unable to properly change with the times. As a consequence, the taxpayers of Nova Scotia cannot be assured that the Province, and its voluntary sector partners, are properly positioned to do the job that is expected of them. They have made sufficient good faith efforts to provide sensible and feasible community supports for persons with disabilities given the system they had to work with. Nevertheless, Nova Scotia is unnecessarily starting to fall behind what is quite practical to achieve in this regard.

It is very important that this recommendation to renew and modernize the CBO system not be seen or interpreted as a mandate to simply spend more.

On the contrary, the crucial guidance from Cabinet should be to use whatever additional resources are provided, to explicitly update the system so that it can achieve more with the resources it is ultimately provided with. The system has been underfunded for a long period and this ought to be corrected as promptly as possible. Nevertheless, *the more fundamental issue is the development and improvement of the system so that it does a better job meeting the needs of the people who rely on it.*

(1.1) Subsidiary Recommendation (One) To Major Recommendation One: **The Province Of Nova Scotia Should Require Of the Department of Community**

Services The Development Of A Five Year Renewal Plan For The CBO System As A Basis For Improved Funding

The present CBO system is failing to lay a strong enough "programmatic" base for the "next generation" of community services that will be needed and expected by Nova Scotians who live with significant disabilities. Fortunately, this can be overcome with the introduction of several new renewal and modernization strategies. Equally fortunate, is that there is considerable consensus within the Province that a new push forward is necessary and desirable.

"Renewal", as mentioned here, refers to the need to see the CBO system as a crucial piece of "social infrastructure" for persons with disabilities and their families, friends and other supporters. This system is like all other essential public supports, in that it not only needs ongoing maintenance, but also periodic investments in its changing relevance to the needs of Nova Scotian society. It has lacked these for many years now and is "winding down" and becoming depleted in terms of its internal capacities to address needs effectively. The "core" of the present problem is that the system has been largely ignored by government as a priority for a sustained period of time, and thus has not had timely investments in its updating. Like any system which opts for "deferred maintenance" and disinvestments, it will gradually breakdown and stagnate. Consequently, it has become static in terms of its evolution and improvement.

It is to the credit of the CBO system that it has managed as best as it can, and that it has not had to abandon the care of people for which it is responsible. Nevertheless, there have been few resources, emphasis or leadership devoted to the actual systems improvement, and this now shows as a falling behind in terms of innovation, best practice and general vitality. There is widespread recognition of this fact both inside and outside of government and a seemingly unified desire to correct this lack.

The type of plan envisioned by this recommendation would be one that focused on strategies oriented to the updating of the system. These would include service innovation and improvement, systems changes of a policy, financing and administrative sort, partnership improvements with the community, service users and supporters and others, human resource and leadership recruitment and development, and safeguards evolution. The specifics of these are largely contained elsewhere in this report and could be enriched with other elements as warranted.

(1.2) Subsidiary Recommendation (Two) To Major Recommendation One: **The Minister For The Nova Scotia Department of Community Services Should Appoint An Independent "Blue Ribbon" Citizen Leadership and Renewal Panel To Oversee And Guide The Revitalization Of The System**

The present system is in dire need of recognition, investment and renewal. While Cabinet and the current Minister need to be the core actors in taking corrective action, this would be greatly aided if there is put in place a prominent body, representing the best of the community, whose sole purpose is to see that the job of renewal is done and done well. Given that the principal long-term agent of the decline has been the neglect of this area by governments, of all political shades, due to declining community advocacy, it is only sensible to counterbalance the future possibility of this recurring, with the institutionalizing for an initial period of five years of a deliberate counterweight. The task of this proposed body would be to prepare a plan each year with the Minister of Community Services, (and perhaps also the Minister of Health), as to desirable and feasible year by year strategic investments in the system's improvement.

This mechanism would be the cornerstone of a new partnership between the Province and the people of Nova Scotia to work together to have in place the best possible arrangements as are feasible given the inevitable tight constraints of governmental financing. It is not ultimately the amount of funding that will predict the outcome but rather the quality of human effort that is made. Therefore it is important to mobilize not just government but also the community towards these ends. This new mechanism would be both symbolically and practically important in doing this.

Similar complementary "people" investments would be sought, as well, from the voluntary sector. The panel would also be charged with evaluating the results of these plans annually, and preparing a public report on the progress or lack thereof, from year to year during this initial five-year renewal period. Part of the preparation of this annual report would include the convening of an annual public meeting to outline progress, and the issues that might need to be faced from year to year. It would be at the discretion of the government, at the end of this initial five-year period, to arrange to independently assess whether this body has been effective, and whether it ought to be continued.

The composition of this proposed body ought to be reserved for a small number, (perhaps eight), of distinguished and progressive minded individuals who are the best that Nova Scotia can muster by way of providing sector wide leadership towards the improvement of the system. This proposed improvement should be judged particularly as it affects the people who must rely on the system. These Panel members would be appointed by the Minister, wit the assistance of a small delegation of voluntary sector representatives, after wide consultation with the sector. The final selection would be characterized by the appointment of people of known talent, independence and probity, but with a decided orientation to innovation, and the sustainable long-term investments that would assure this result. Their appointment would be renewable annually. Once the body is established it will assume responsibility for the updating and replacement of its members, as people might come and go over the period.

The Panel would have sufficient resources to meet regularly, undertake a limited amount of consultation and research, and to make itself accessible to ordinary Nova Scotians so that it can work closely with their concerns and give sound direction to government each year as proposed. It can be anticipated that renewal and improvement will require the thoughtful engagement of many people at many levels, and the Leadership and Renewal Panel will necessarily have to act as a key and prominent catalyst for change. Its very presence is precisely the kind of symbol that is needed in Nova Scotia to indicate the seriousness of government in advancing the situation. It will go a long way to dispelling the present psychology of discouragement by its positive agenda of forward movement.

Its success or failure will be in building grass roots momentum towards a vision of a "next generation system", complete with a revitalized community and governmental sector working together for change. The ultimate source of strength in the future will not be in a reliance on government, so much as an active and engaged citizenry that is "out ahead" of government. This recognition that a revitalized social movement is needed, may not be entirely shared by those who place their hopes on bureaucracies and systems, but the past has ample evidence that wherever this citizen movement exists progress is imminent.

(1.3) Subsidiary Recommendation (Three) To Major Recommendation One: **The Leadership and Renewal Panel Should Initiate And Oversee An Ongoing Strategic Leadership, Renewal And Innovation Training/Education Plan**

The Panel would be remiss if it created the impression that change could come quickly and without adequate and thoughtful investments in the many people of Nova Scotia who will make the CBO system into what it could be. At its roots, change is ultimately an achievement of people themselves, more than the organizations that they are associated with. *The task of the Panel is therefore a highly educational and developmental one of systematic "people building" investments to help prepare and strengthen the many people who would be involved in moving the system ahead.* This would include, but not be limited to service users, families, professionals, managers, civil servants, community board members, involved academics, employers, advocates and possibly many others who are interested in future and progress and want to be part of helping create it. The plan would be long term in nature with annual increments.

The intention here is not to undertake indiscriminate mass trainings and conferences, but rather to laboriously and exactingly target the crucial areas where an educational investment in the people of Nova Scotia would show the greatest promise of long-term improvements in the system of residential supports. Preferably, such highly focused investments would be made across conventional organizational boundaries, in order to better link the many talented people of Nova Scotia in a common overarching purpose, and to build the essential capacities needed in order to move ahead in a meaningful way. It would also strategically position interested Nova Scotians to be aware of best practice in the field, and to be in touch with key practice leaders and innovators inside and outside of Nova Scotia.

The principal areas that would likely require strategic educational investments would be broadly as follows, though the precise year-to-year priorities would have to be set by the Panel;

1) Improving Judgment and Decision-Making In Leadership And Supervisory Personnel And Volunteers

2) Effective Strategies For High Quality Personal Supports

3) Effective Strategies For Meaningful Service User and Family Influence On Service Practice

4) Improving Supports For The Most Difficult To Serve

5) The Creation of Intentional Personal Safeguards

6) Strategies for Strengthening Citizen Oversight, Effective Decentralizations and Transparency of Operations In Both Community Providers And The Government

7) The Many Ways To Assure That Residential Supports Will Result In Real Homes For People Rather Than Mini-Institutions

8)Strategies For Encouraging Highly Relevant Innovations

9) Supporting People To Undertake "Bottom Up" High Quality Service Design And Operation and

10) Leadership and Change Challenges Pertinent To How Support Is Rendered.

The preceding all should include one manner or another of examination of key values and theory as they apply to the practical issues in people's lives. There are, of course, many useful topics that would be beneficial to pursue, but these certainly would be indicative of the kinds of educational investments that would be worthwhile, if done thoughtfully and over a significant period of time.

(1.4) Subsidiary Recommendation (Four) To Major Recommendation One: **The Leadership and Renewal Panel Should Collaborate With Other Jurisdictions To Gradually Establish Or Utilize The Educational Resources Needed To Revitalize The Nova Scotia System**

The specific capacity to produce the types of educational resources indicated here does not currently exist in Nova Scotia. It would be difficult to imagine such a comprehensive leadership educational resource, even at a national level, though its probable utility is obvious. It will therefore likely fall to Nova Scotia to develop this, in the interim, in the form of some manner of actual or even "virtual" educational institute. This kind of capacity could be attempted solely from within Nova Scotia, but this would be improbable and would not properly tap the many resources outside of Nova Scotia that already exist regarding these sorts of subjects. It would be wiser to not duplicate these, but rather ensure that they are as economically and strategically used, as may be possible, to act as in their capacity as a catalyst for development in Nova Scotia. If this were done gradually over the years, then it becomes more possible and likely that Nova Scotia would eventually have available to its people the best of the available training and advice in the field at the least cost.

This desirable long-term result is not likely to occur if the task is undertaken only on a sporadic basis, as this crucial input and "people builder" will tend to be sacrificed to direct service costs, given the incessant reality of urgent service demand and emergencies. Consequently, it is highly advisable that some permanent "internal-to-Nova Scotia" long-term capacity be established to continue to provide acutely relevant education on best practice. The quality of considered thought given to such an annual program of catalytic education cannot be underestimated, since it is a resource so easily wasted if the education actually offered is too weak in light of the actual challenges to be faced. Given that educational resources are always going to be scarce, it is important that the task described here be undertaken carefully and responsibly, particularly in the proposed initial five year renewal "window". Whether some sort of institute could be formed to act as the anchor for this initiative will have to be determined by the Leadership and Renewal Panel.

It may be possible given the relatively short distances involved, and the value to all of the parties, to explore two key kinds of regional educational collaborations. One would be an Atlantic Canada version, and another would be one that tapped into the depth of talent and good examples that exist in the nearby New England region of the USA. Both are possible, as would be other alliances across Canada. These needn't be comprehensive alliances, but could rather economically focus on matters that have the most promise for productive results. Human development resources must always compete with operational expenditures, and therefore must expect to be questioned intensely as to their ultimate value.

(1.5) Subsidiary Recommendation (Five) To Major Recommendation One: **The Leadership and Renewal Panel Should Sponsor An Annual "Progress and Change" Conference For The Field**

be very timely that an annual conference be held regarding progress and change in the field that brought together people with the express intention of encouraging them to struggle, dialogue and learn as it relates to what is desirable in terms of best practice. This occasion would be an ideal opportunity to establish a broad based consensus to rally people in Nova Scotia around the challenges to be faced in preparing for and proceeding into the future. There are currently few points that exist for such a unifying of vision and effort in the system, and this would be a valuable starting point for renewal especially if the program was consistently weighty and challenging.

Section Two: The Expanded Use Of More "Personalized" Support Arrangements

Observations and Comments: **The CBO Model Struggles With Strong Elements of A Custodial "Service Facility" Culture As Opposed To One of "Real Homes"**

Though the CBO sites are technically unlicensed settings, many are nevertheless seen as being, in essence, "service facilities" rather than the "real homes" of the people. This is said keeping in mind the same general sense of "real home" that most ordinary citizens would operate with. This strength of this tendency is not uniform, of course, as there is clearly considerable variability within CBO settings. Nevertheless, this tendency is widely present as a factor, and ought not to be dismissed as a minor matter, since it has a great bearing on the quality of what is experienced by each person served. The essential challenge is both that of *preserving the home as being principally that of the resident and keeping it a "real home"*.

What most people would think of as their "home" ought to serve as a guide to judge what elements of this are afforded or not to service recipients. This should be seen in comparison with what an ordinary citizen might expect of their "home." For instance, it is highly instructive to note that the majority of CBO residents, unlike ordinary citizens, have practically no "say" in where these homes are located, which type of accommodation is selected, with whom they live, what the key rules of the home are to be, who are permitted in as staff, and so forth. The absence of any of these would be considered by most Nova Scotians to be a violation of the sovereignty of their home and their place in it. Yet for residents of "homes for special care," it is clear that a quite different meaning of "home" is at work. This is often that of "facility," i.e., a quasi-public place in which care is provided. A "facility" is not at all the private, personal, intimate place in which a person can be more fully herself or himself, that most people insist upon when they think of what "home" is for them.

Typically, "facilities" are more quasi-public places in which one resides or has shelter and meals, more than that they are places that one has fashioned a "home" from. Even the language of such services belies this more impersonal character of the homes provided service recipients, e.g., "settings", "sites", "facilities", "placements", "the home", etc. Such a drift towards homes becoming facilities is accelerated by the invasion of the home by either the agency's own or the government's bureaucratic culture. This is most evident in the extent to which the homes of people become dominated by their identity as "outlets" of agency policy and practice, and workplaces for the staff. This same phenomena is often properly called "mini-institutionalization."

This phenomena of "mini-institutionalization", widely noticeable throughout similar settings in other jurisdictions, is not "per se" solely a function of the CBO service model, but rather a tendency that emerges when the character of the home slips under the control of external parties or forces. It is most highly associated with custodial settings that are dominated by an ethic of "care" more than "home"—hence the widespread acknowledgment of the presence of a "mini-institutional" culture. Since the problem lies more at the level of ethics or value, it is best seen as attitudinal in origin and can be similarly challenged at this level.

What is often noticeable is that the phenomenon tends to diminish the more personalized the living arrangements become. It is far less evident in homes where the person is the dominant identity, and where the supporters hold themselves to an ideal of "home" as a test for their conduct. For instance, the practice of residents leaving their homes in the morning only to find that all sorts of people, unknown to them, have used their home for a meeting without their permission would be distressing to most ordinary citizens. Yet such practices are not unheard of, and may even be shrugged off by the participants as being irrelevant to worry about. However, close examination would reveal the distressed resident would "have a point." Most people would consider their home to be a place where strangers cannot enter and come and go without their explicit authorization. Yet this right and courtesy is easily suspended when the agency supporting that "home" treats that home as something over which it has sovereignty rather than the resident. Using the perceived incapacity of the resident as an excuse to justify such invasive and disrespectful conduct is easily understood when one sees that such a home has in reality become a facility and the resident a "client".

It is naturally not meant by "home" that all manner of persons emphasize the same elements of home life as being important to them, or that some homogenized or sentimentalized notion of "home" is at work here. Rather, the intention is to forthrightly look at one aspect of a culture of service that has pronounced tendencies to turn peoples homes into "facilities." This begins by not creating the home with the person in mind, but rather creating homes and then asking people to move into them. What is being asserted here, and wherever this issue arises, is the positive value of having the character of one's "home" grow out of the personality, necessities, and preferences of the resident. This, in itself, is hardly a radical proposition. If taken seriously as a core principle, it constitutes a substantial challenge to the now widespread agency dominated and custodialized culture of many community residential services.

Observations and Comments: The Question Of Properly Specialized (Individualized) Support Arrangements For Particularly Challenging Individuals

A particularly difficult question for all manner of residential services is that of how to deal with specialized sub-groups. Who these people might be is varies from persons with self-destructive conduct, persons with mental disorders which are either very difficult to diagnose or treat, individuals with assaultive behavior, persons with addictive histories, persons who are manipulative and anti-social, persons with extensive medical or physical care issues, persons in need of supervision, those with infectious conditions e.g. HIV, tuberculosis, hepatitis etc. In the case of the CBO system, the advancement of more individualized support arrangements would give the system greater capacity to design arrangements that are explicitly for only one person.

By "capacity", it is meant not only the capacity to design such arrangements but also to carry them out with a measure of quality.

Finding and supporting exactly the right people to work with particular individuals may prove to be very difficult, even at the best of times, and thus "capacity" in human terms must be properly appreciated as being central to what can actually be accomplished in practice.

This question of the proper "specialization" of supports could be distinguished from the simple individualization of supports given that a particularly difficult individual may indeed obtain a relatively personalized set of supports. Nevertheless, if these arrangements still prove to be irrelevant to the person's needs, then the individualized options will have been unsuccessful. A classic example of this would be in the instance of a person with significant behavioral problems requiring highly dependable supervision being given persons to supervise them that are inept. The supervision is indeed individualized but inadequate. Hence, failure will result. Thus, what is needed in such an instance is a better fit between what people need and what they get. Individualized supports are not exemplary just because they are present. They must also be highly tied to what people need and therefore pass the test of relevance. *Irrelevance of supports is quite possible within individualized arrangements and thus a "higher" test of their merit is this one of relevance to the persons crucial needs.*

It is even more unlikely that a service will prove highly relevant to the specific needs of a given person if the people providing the service rely too much on "formula" thinking, with the consequent standardization that flows from this. Yet, once services do get set up, they tend to rather tenaciously adhere to the model or pattern that was put in place at their founding. Under such conditions, there is always a pressure present to fit the person to the pre-existent model, rather than to construct a support arrangement original to the person and their needs. This is even more likely to occur where the pre-existent model has met with some success with people, as this same success enhances its credibility. Nevertheless, even this success may prove to be illusory if there are not regular adaptations made to continuously alter the practices and support patterns to better address where the individual is at today. The skill required to do this is substantial and may often require the presence of people with unusual talents, experience and commitments in their "specialty".

At present in Nova Scotia the development of this kind of "specialty" capacity is not specifically provided for *at an individual level,* nor is there a specific mechanism and capacity in place to support its evolution. The CBO system has been very creative in trying to support many individuals, but this is often hard to do well, particularly in group living contexts. The agencies involved in supporting such difficult people do "muddle along", but this seems insufficient as a safeguard for such a crucial element of the community support system. If the most difficult to serve can routinely be assisted with competence, then it permits a higher level of public, family and professional confidence that the system is sound. These more challenging individuals can, in theory, be quite responsibly supported in the community, but *only if the supports provided to them are the "right" ones.* Thus the CBO system must carefully consider whether this capacity is being properly established .The general public and the relatives of such persons automatically assume that this is the case, and trust the system to ensure that this capacity exists as needed. At the moment the ability of the providers to manage this well is limited particularly when individualized arrangements are considered. There exists no specific system strategy to oversee and safeguard the support of persons whose needs are significantly more challenging than others, nor is there much by way of formal supports to improve this capacity. This is not meant to say that such persons are being neglected by either the providers or the government, but rather that these kinds of possibly intense specialized supports are not organized as a specific sub-system capacity of the CBO system. This arrangement may be fine for persons who do not pose unusual service delivery challenges, but is insufficient when it comes to the most difficult and worrisome people to serve. It would be very desirable for the CBO system to strengthen its capacities to assist these sorts of individuals. To do so it would need to carefully address the interrelated concerns of coherent service design, the strengthening of staff selection, orientation, development and supervision, the creation of intentional personalized safeguards and the provision of technical assistance and other problem solving and developmental supports. These are classical "capacity building" measures and would be highly relevant in strengthening the ability of the CBO system, (and its successor,) to serve even the most difficult to serve.

Goal: Establish The Conditions Whereby Individuals (and Families) Have The Best Possible Chance to Get Precisely The Supports They Specifically Need

(2.0) Major Recommendation Number Two: **The Nova Scotia Department of Community Services Should Gradually Reshape Its CBO Residential System In Order To Make Flexible Personal And Family Supports The Core Modality Of The System**

The focus of the present system has been unduly distorted by the historical emphasis on residential sites and locations, more than the actual supports that the resident needs in order to have the kind of life or lifestyle that would be optimal for him or her. Not uncommonly in such an emphasis, getting a person a "placement", or "bed" or program "slot" becomes the preoccupation. The authorization for this view is contained in the now outdated "Homes for Special Care Act" that still dominates practice in Nova Scotia. The alternative is to intentionally reshape the goals and patterns of the present CBO system to correct this. Such a major shift is quite practical at the programmatic level, though it will likely take at least five to ten years of steady work to ensure that the new pattern is well established enough to eventually make it the more dominant pattern. In many ways, such a shift is comparable in scope to the now historical shift in the field from institutional models to community-based services that began over a quarter century ago.

In the more contemporary instance of shifting from a community facility orientation to one that emphasizes "person centered" support models, this trend has been accelerating in the field since it was rediscovered more deeply that that the best support arrangements were those that directly grew out of the identity and needs of the person themselves. This approach requires that supports be configured with the person and their needs as the "template", not a pre-existent (and usually standardized or uniform) service model. In both the cases of children and adults still highly involved with their families or other "natural" supporters, it also means that the support could be developed with the partnership, not only of the person, but also the people close to him or her, should this be appropriate.

(2.1) Subsidiary Recommendation (One) To Major Recommendation Two: **The Province of Nova Scotia Should Introduce New Legislation To Supersede And Update The Present "Homes For Special Care Act" In the Direction Of Fostering More Personalized Support Arrangements**

Though the present CBO system is a largely unlicensed system that does not directly encounter much of the formality of the current "Homes for Special Care" Act, the Act nonetheless still remains the principal authorizing Act for residential care in the Province, and it has not been updated for decades. This omission is all the more surprising given the rapidity with which the whole field has evolved in the last few decades. The replacement of the Act is therefore timely, providing that a new enabling piece of thoughtful legislation is carefully introduced that sets the stage for the "next generation" of supports. Though not urgent, it would mean that Nova Scotia can be better positioned to both make desirable up-to-date options available to its citizens that need them, and be able to convert its increasingly outdated conventional "fixed model" services into more desirable personalized and flexible support patterns.

The type of Act that would best achieve this would be one that meets several key criteria. The most important of these is that the emphasis be shifted from establishing and licensing places or locations, to one of establishing flexible and personalized community support arrangements designed and guided from as close to the individual as possible. In this it is important that the Nova Scotia Department of Community Services and its provider system become much more able to partner with service users and their supporters to create funding and administering arrangements that, *as much as possible, enable these persons to directly shape the services and supports they receive.* This is a quite significant shift from the more controlling and paternalistic pattern of professional and manager dominated residential services that grew out of Victorian charity institutions. Nonetheless, it is consonant with the emerging, and quite legitimate aspirations, of persons who live with various impairments, to be master of their own lives and more forthrightly full citizens of the community.

By envisioning and eventually proceeding with such an Act, the Province can rightfully signal its support for the legitimate hopes of people with disabilities and their supporters. Such a sign of moral support for change, need not be seen as a commitment to supply endless resources for possibly expensive residential care, as simply spending money alone is not likely to benefit these individuals. What is needed is much more an emphasis on "value-for-dollar", i.e. improved cost benefit ratios, given that the aim is to target (always limited) resources, so they are spent as directly as possible *on what people most need.* The proposed "Act To Provide Personal Community Supports For Persons With Disabilities", (as proposed by this evaluator), should ensure that the role it assigns to service users and their supporters gives prominence to their proposed central role as authorized shapers of the supports they might receive. It would also require that they be assisted with this admittedly new and challenging role, so as to better be able to optimize their contribution.

The terms "personalized support arrangements" may be elusive for some people and, therefore, it is useful to add a measure of clarification as to what these mean. Personalized support arrangements are intended to be specific measures of support tailored to an individual given the particular needs they have for assistance. These may be provided to the person, in or in relation to their own home living arrangement, or even offered to the person while they are resident in someone else's home on a temporary basis. The quality of these can be expected to vary, as it is possible to provide these poorly as well as proficiently. The key factors in predicting the quality of supports will be their relevance to the persons fundamental and important needs, the dependability of their presence, the quality of the people rendering them, the measure of influence the person has on how these are selected and implemented, the adequacy of the supports in terms of the amount provided, their affordability given their benefit, their ability to be modified as needs and circumstances change and the extent to which they enable the people to achieve the lifestyle goals in the community that they may have.

(2.2) Subsidiary Recommendation (Two) To Major Recommendation Two: The Service User and Their Supporters Should Be Entrusted On A Delegated Basis With Sufficient Authority To Influence The Character Of The Supports They Receive

It is often not well appreciated by many people, the extent to which residential services can take over control of an individual's life. This becomes all too clear when they themselves experience this, but then it is often too late. Residential services may be invasive of even the most intimate details of one's personal life, and it is very difficult to restrain this tendency even in instances where the people involved are conscientious and scrupulous. This is because the domination of people's lives is usually done unconsciously and with little intention to control. Nevertheless, the risk of doing so is real, and more farsighted administrators and planners have seen the need to fundamentally change approaches to practice, so as to strengthen the influence of service users and their supporters to offset the "domination of care". One key element of these emerging strategies is the provision, to service users and their supporters, of sufficient personal authority in the service formation and management process, to consciously offset the substantial powers traditionally assigned to funders, providers and professionals. This creation of a more level playing field, is not by any means a panacea, but it does offer real hope for a shift in the culture of how service is rendered in instances where it is taken up with integrity.

The key "powers" or authority that are most needed by individuals, to offset the commonly invasive and controlling presence of conventional residential services, would be those of the authority for them to imagine better supports, and to plan how these might be attempted, the authority to be able to refuse to participate in arrangements they believe to be damaging to their best interests, to be able to propose and negotiate what they believe to be superior alternative arrangements, and the authorizing of arrangements that would enable them to enjoy a delegated measure of accountable control and direction over available resources used by the system on their behalf. The specific aspect of individualized funding will be taken up in subsidiary recommendations that follow.

The exercise of these limited powers is normally undertaken on a delegated basis where the funder permits their exercise subject to regulations that oversee their use. Consequently, individuals who show poor judgment or irresponsibility in employing these can be duly restricted in their ability to take advantage of them, based on principles that are set out in advance. In this way, these uses of the delegated authority of the funder, are "conditional participation rights" extended to the service user and their supporters. Normally, as in any honor system, the presumption of their good use is extended to individuals until such time as they demonstrate cause for the restriction of these advantages. Even then, the remedy itself ought to normally be the addition of further supervision and assistance, rather than the outright suspension of these rights.

There are many shades of opinion possible on matters such as these, even at the best of times, so it is important to recognize that a shift towards a more egalitarian distribution of powers in everyday service practice is an inherently difficult challenge. The introduction of practices such as these has already taken place in some agencies in Nova Scotia, so it can be assumed that the proliferation of such options will become more widespread once the concept receives further official sanction. Nonetheless, the "state of the art" in regards to such innovations is presently relatively basic, and it should be anticipated that the ability of the Province to guide such new patterns will need to evolve with the experience gained. For this reason, it would be prudent for the introduction and regulation of such participatory options to be undertaken with a view to periodically evaluating the progress and problems that come with their more widespread use. By doing this, a premature "freezing" of nascent experience into regulations can be prevented.

The potential service practices and operations involved that could, in theory, become matters that the service user may elect to influence should not be limited except for very compelling reasons. Hence, any aspect of service practice ought to be *discussable* and *negotiable, unless specifically excluded by the funder*. Thus matters such as staff selection and supervision, home selection, priorities, focus, quality, safeguards, and even minor or annoying elements of bureaucratic administration may be matters that service users seek to influence and modify. After all, it is their service, and restricting them from a role in modifying it does not seem defensible or constructive.

(2.3) Subsidiary Recommendation (Three) To Major Recommendation Two: **The Nova Scotia Department of Community Services Should Revise The Present Residential Service Program Categories**

Though this review is concerned mainly with the CBO system it should be recognized that the distinctions between it and other community residential models in the system are somewhat arbitrary, and tend more to reflect the timing of the appearance of the these options historically. The distinction between institutional models and community residential options remains a useful one, as it properly helps to identify the institutions as being apart from community. From a service user perspective, the maintenance of the variety of community residential categories tends to create multiple residential categories where a single one would be preferable. If the Department of Community Services were to see these options as simply being one of many options potentially available to service users, then having a separate system for each would be unnecessarily rigid and redundant. It is the recommendation of this evaluator that these categories of community service be eventually merged into a new single funding category entitled "flexible personalized community supports".

It is recognized by the evaluator that something equivalent to this has been emerging into common practice over the past years in Nova Scotia but, even so, it would benefit from a measure of formal recognition as it reflects a willingness to have the system no longer rely on categories of service (i.e. "fixed models" and instead rely on the template of continuously variable individual supports.

The advantage of such a change would be to help simplify the system, and to make it possible to take existing community-based individual and small congregate care arrangements, and readily convert them to more personalized options without unnecessary bureaucratic complexity. The legal complexities involved would depend upon how soon a new authorizing Act could be brought into existence, as some of these structures are embedded in law and regulation. Nevertheless, the overarching intention would be to create a single funding stream for any community support arrangement, thereby making it very easy for an individual to move from one arrangement to another, or to have their support arrangements modified. The more that such changes are enabled to be a minor matter, the more responsive and flexible the system can be to the ever-changing circumstances of people's lives.

(2.4) Subsidiary Recommendation (Four) To Major Recommendation Two: **The Present Classification System Should Be Replaced By A Simple Eligibility and Priority System**

The CBO system has existed somewhat outside the present classification system, and thus has managed to escape the need for individuals to be assessed and assigned to pre-existing residential categories within the CBO system. The individuals still need to be classified. Such a classification system reinforces the reliance on "fixed" service models, and is therefore inconsistent with the major thrust of this review towards a system that better responds to the needs of individuals. Again, the classification system is integral to the arrangements built into the, now dated Homes for Special Care Act, and may need to be phased out in conjunction with the Act overall. Its replacement should be a system that determines an individual's eligibility for service and which assigns them a priority for funding as needed. This need not include the establishment of formal "waiting lists" since the rules for moving off of these and being assigned priority on them are usually non-existent thereby diminishing their utility and credibility.

The easier of the two to establish is eligibility systems, and virtually all systems have them, even when these are only poorly attended to. The more difficult element is usually that of priority setting. There are many contributors to settling this designation such as the changing conditions of people's lives, the availability of resources, the competition between systems and individual goals and so forth. A given priority ought not to be a permanent designation for a person given that their needs can change quickly. Hence, systems that establish designations that are immutable in practice are unduly rigid. It is also true that systems that seek refuge in formalized priority setting as a way to avoid the painfully difficult negotiations that arise with individual cases, are being unrealistic since there will always be anomalies. It is also useful to recognize that while there may be Province wide priorities, this does not exclude the possibility of simultaneous local or regional priority setting. In fact, at the individual level, it is preferable that priorities be set by the system as close to the individuals affected as possible. *This does introduce some regional variability, but this should be the case if what people need varies.*

(2.5) Subsidiary Recommendation (Five) To Major Recommendation Two: **The Province Should Reconsider And Reverse Its Recent Decision To Move Home Care For Disabled People To The Health Department**

It is often the case in complex bureaucracies, that the effects of policy changes in one part of the system end up having unintended consequences in other arenas. This appears to be the case in regards to the recent decision, in which the Department of Community Services cooperated with, to transfer their home care program,(or what is often called by some people as "respite" or "family support"), to the Department of Health. While this was intended, quite laudably, to help create a more seamless generic home care system overall, it will nonetheless severely damage the capacity of the Department of Community Services to mount a more systematic effort to provide flexible personal supports for persons with disabilities. It would be extremely important for these supports to be returned to the jurisdiction of the Nova Scotia Department of Community Services, and help fill in the gap of supports, in their system, to the "natural" supporters of people. Such systematic and flexible family support would go a long way to prevent the unnecessary and premature "residentializing" of people by offering them a less invasive alternative. It is also predictable that this recent move will tend to push "family support" much more into the (usually more expensive and medicalized) "home care" paradigm. A "flexible family support" model, (particularly if family governed), is usually vastly more attuned to non-medical family supports, and thus more relevant for most matters involving persons with disabilities.

(2.6) Subsidiary Recommendation (Six) To Major Recommendation Two: **The Nova Scotia Department of Community Services Should Permit And Encourage Funds Currently Held In Established Or "Fixed" Residential Models To Be Used More Flexibly On Behalf Of Individuals**

The present CBO system does not technically prohibit the "unbundling" and re-use of funding going in to maintaining existing households but the incidence of doing so is quite rare. This tends to "freeze" supports into their original pattern, even though individuals might come and go from the same household over time. If a person is to get a different pattern of support it is usually only by exchanging one "fixed" household for another. This practice, of course, restricts the field of available choices to nearby existing residential services of largely the same type in the CBO system. It does not add to the array of choices, thereby leaving the system "frozen" and unresponsive to needs that do not sit well within existing service configurations. It must be remembered that more than 75% of existing residential budgets are essentially locked into full time equivalent positions (FTE's), particularly in the CBO models. If this pattern cannot be changed then it would be predictable that the present FTE pattern would in actuality be the driver of "needs" more than the actual needs of the named service users, if these positions become an inviolable part of the pattern of support and budget. The remedy to this problem is highly dependent on whether the resources that have already been allocated can be rather easily used in a different way. *The crux of the matter is that it is impossible to respond to variable individual needs if ones spending pattern remains "frozen" into a single pattern in perpetuity.*

Since these patterns get institutionalized in service contracts and budgets, these same tools could also be used to "unbundle" the funds that these positions rely on. This would mean *the establishment by the Department of Community Services of an explicit administrative mechanism that would permit "bottom-up" unsolicited and solicited proposals to emerge that could eventually lead to the deliberate re-use of existing funds.* These proposals could be negotiated by their proponents, *on their merits,* with the funder. Those eligible to advance such re-use proposals would need to include service users, providers and even departmental employees. In all likelihood, the "trigger" for such a re-use proposal would be the changing needs, (or perceptions of them), by service users and their supporters. This effort could be carried forward by any assisting party, in collaboration with the affected person or persons, if such collaborators are authorized to do so by the service user. It is also possible that the Department itself, through normal "request for proposal" (RFP) tendering mechanism's, or even routine contract modification mechanism's, essentially ask for original or innovative proposals to reshape existing services in the direction of options sought by service users and their supporters. In some jurisdictions service users and their supporters have played a decisive part in both the formulation of the specifications of what type of supports are being sought and the adjudication of the resultant proposals. A nearby example of this would be the Massachusetts consumer guided RFP model as well as their "unbundling" of all sorts of former group living arrangements.

The essential goal would be to make the re-use of *existing* funds become administratively more convenient and routine, such that there would not be a great deal of cumbersome bureaucracy to impede the necessary flexibility needed with resources vis-à-vis service users. It would be obvious to many observers that this could be disruptive to present residential arrangements that involve multiple service users, since the departure of even one resident without a "replacement" resident, would make many CBO's unviable. This, of course, is the very problem that a move to individualized options would considerably lessen i.e. *the use of patterns of service that force service users "unnaturally" in to home situations that they would never have sought if there were an individualized alternatives available*. Thus, what is in its original expression a "disruption", may nevertheless position the remaining residents to eventually pursue their own personalized support arrangements.

The experience with such "unbundling" or "supports transformation" processes elsewhere, has not shown that service users and their supporters ultimately end up wishing they could return to, (even small) involuntary congregate care arrangements in the community. (See the "microboard" experience in British Columbia, individualized funding in Alberta, "shared living" in Massachusetts, the Onondoga Community Living agency experience New York, and so on). This mirrors what was witnessed on a larger scale at an earlier period with institution resettlements, where it was initially argued that community living was a reckless or misguided experiment that only extremists might advance. In reality, the claims that listening to the desires of institution residents and their supporters would lead to some sort of tragic error have proven to be alarmist and antiempirical. Not surprisingly, the fact that the interests of many parties in preserving their place in the status quo of the day, actually were possibly at the root of the defense of the existing system, was never properly acknowledged. Thus, the lessons of this prior significant transformation of supports may have been lost to many. Today, we again may witness arguments that the achievement of personalized and flexible supports, based on taking seriously the aspirations of service users for a better life, is misguided and naive. Yet, the available evidence for this assertion is contradicted by the examples of where it has actually been seriously attempted, including in Nova Scotia and elsewhere. There may exist waiting lists for CBO's, but this is likely due to the fact that even better options are either unknown to the registrant or seen as unavailable.

(2.7) Subsidiary Recommendation (Seven) To Major Recommendation Two: **The Department of Community Services Should Establish A Form of (Elective) Flexible Individualized Funding That Would Permit Services Users And Their Supporters To Have Substantial Influence On How Resources Devoted To Their Use Are Utilized**

As has been indicated in previous comments and recommendations, it would be very advantageous both for the service user, and the most relevant use of scarce resources, if the service user could play an influential role in decisions regarding resources that might be targeted to them. However, not all arrangements to do this are equal, and therefore it is useful to try to establish a "better" system to do this rather than an inferior one. It may not be all that well known that there are in actuality a diversity of examples of these sorts of individualized financing mechanisms. Each have their particular strengths and weaknesses, and it would be optimal if the Department of Community Services was as careful as possible with the introduction of such elective options, so that the greatest long-term advantage can be gained. What follows is some guidance to this end.

A key distinguishing feature of individualized funding arrangements revolves around the question of who is fundamentally the "owner" of the funds. If the funder is the Province of Nova Scotia, then the funds available are necessarily those of the taxpayer and are governed by the will of the legislature. In some forms of direct cash assistance from governments to individuals, such as is seen in family benefit payments, the funds are transferred from the control of government to individuals. In these instances, "public" funds become "private", subject to the restrictions, eligibility and so forth imposed by the originating legislation and regulation. It is the view of the evaluator that such a direct payment system would not be necessary in order to achieve the kind of strengthened service user influence described in this report. Were this type of arrangement to be initiated at this point, it would be in the context of considerable bureaucratic, service user and provider inexperience with the conditions it would create. A less radical approach, that would largely achieve the equivalent effect, would be to leave the ultimate control of any such funding in the hands of the funder, but require the funder to enable the service user and their supporters to have conditional influence on the use of these funds. This would occur on a "delegated" basis from the funder to the individual, *subject to whatever conditions the funder may need to operate such a mechanism prudently*. The funds themselves would ultimately be clearly government funds, *but their use would guided by the person concerned on a "shared" basis with the government*. This form of delegated authority would permit the Department of Community Services to develop an *elective flexible individualized funding option*, relying on its present authority to decide how residential services are to be properly administered. At the moment, community service providers are enjoying, on the same (delegated) basis, the equivalent authority described here. It is patently unfair that this option has been denied to the many service users and their supporters who have as much comparative integrity, competence and wisdom as do the providers. In fact, some providers have already extended this delegated authority to the service users they support. They have done this as a matter of preferred practice, based on the premise that service users ought to have this sort of influence on how they are supported. The Department of Community Service is aware of this, and permits it to occur by deferring to the provider and the service users concerned.

Consequently, it is quite accurate to say that a version of informally authorized individual delegated funding is already in place at the practice level in Nova Scotia. Though the practice is not particularly widespread, it is by no means new to the system. What would be new would be whether the Department of Community Services were to inform service users and others that they *could elect to negotiate and employ such arrangements when these might be to their advantage*. It is not the view of the evaluator that such options ought to, or need to, be used routinely as a standardized operating method. Rather, what is recommended here is that the mechanism to do this be made available to any eligible service users *should they elect to use it*. It is preferable, in any case, that unfamiliar mechanisms or approaches be introduced gradually, so that the manner of their use can be gradually improved through the accumulation of actual experience with these novel and unfamiliar methodologies on a small scale.

It is very important that this variety of individualized funding *influence* not become confused with arrangements in which a person is awarded a fixed amount of funding as a funding *entitlement* in perpetuity. The funding needs of individuals can be expected to vary as their needs change, and as less expensive ways of meeting needs become available. Consequently, it is not in either the public interest, or in the interests of individuals to "lock" spending into a particular pattern. After all, reserving the right to change one's mind about important matters is a sensible caveat. However, it does mean that the funder, the individual and the involved provider must have available to them *the ability to negotiate changes in the funding arrangement on a timely basis*. After all, the point here is to not "lock in" spending patterns in the interests of flexible responses to individual need. Many service users and providers would understandably like the assurance that hard won amounts of funding that they depend on not be jeopardy of being withdrawn. Nevertheless, this prerogative is not one that governments can absolutely give away, as even service purchasing contracts are usually conditional on the government having the funds in the first place. Also, governments have a responsibility to economize in order to obtain the best use of existing resources and the granting of inviolable "in perpetuity" entitlements would make the exercise of this duty unworkable. Further, it is in the interests of the service user and funder that existing funds be re-used in other ways, if the alternative use is superior to what is in place, even where the new option is less costly. Though it may shock many people, the quality of a service arrangement rests not in how much is spent on it, but rather whether it is the right thing for the person and their needs.

It is nevertheless highly useful if the service user reserves the right to refuse participation in support arrangements that they judge to be seriously deficient. This right already exists for service providers. Service users ought to have the commensurate right to propose and negotiate a more desirable support option. This would include being able to propose, to both the funder and provider, options that are different in net cost as well as the pattern or distribution of expenditure likely to be involved. The final result would then be a matter of negotiation, as it has always been between providers and funder. The difference is essentially that the service user and their supporters would have the formal status of being recognized "players", even in instances where the service user is currently an "unfunded" person. After all, it has always been the case that individuals could approach the Department seeking eligibility and funding.

Similarly, the funder always has had the right to answer "no", "maybe", "yes" or whatever. The proposal contained here simply adds formal "participatory" standing to service users with no specific financial obligation accompanying the adoption of this practice for government. It is largely a strategy for increasing flexibility and service user influence on existing funds i.e. funds already being used recurrently by the system. Thus, it does not need to add to the net cost of services except insofar as the funder authorizes this. Thus the extension to the service user of influence on funding does not constitute a recipe for a "budget blowout", except in the instance where funders behave recklessly, and agree to spending levels they cannot afford. *Flexibility in budget use should not be confused with budget expansion, as they are quite separate matters.* There are several more features that ought to be incorporated that would bring useful advantages for service users. One of these would be the option for service users to have "portability of funds" be something they can negotiate. By this it is meant that service users may elect to negotiate the transfer of the funds allocated for their supports from existing providers to another incorporated provider. This may even include any eligible organizations that have not historically been involved as providers with the Department. By implication, service users may elect to "shop" for another provider at any point. Nevertheless, the confirmation of this status, as the service users preferred provider, on the prospective provider would be subject to funder approval.

Another useful feature, that technically already exists, but is rarely used, would be that service users and their supporters have the ability to establish a new provider organization should they judge this be in their interest. There are many gaps in terms of what is on offer "out there" in the present array of service providers, and it is only reasonable that other (new) providers who might offer advantages to service users be able to readily develop. At present, the financial, technical and management capacity for citizens to organize the creation of new provider entities is very restricted. The net result is that the CBO system has seen a rather low rate of new provider entrants to the system. What would accelerate the possibility of a greater number of new entrants to the provider system would be the availability of assistance in developing such entities. This would be most important in regards to supporting the kind of informal grass roots groups that, (typically), are all that originally exists when an unmet need is being taken up.

It is also true that many service users and their supporters are very unlikely to pursue their inclinations towards improved service options if they do not have knowledge or confidence that there is actually a better option. They may very much need help with the "imagining better" part of things, to say nothing of how in the world one could negotiate these improvements into practice. Often better ideas are not a matter of spending more, but rather rethinking how practice and spending is currently done. It is a common observation that such imaginative rethinking of service practice associated with useful innovation, is dramatically more likely when the service user or their family gets good advice and support from innovation minded people. What follows in the next recommendation will assist with this need.

(2.8) Subsidiary Recommendation (Eight) To Major Recommendation Two: **The Department of Community Service Should Ensure That Service Users and Their Supporters, Community Providers and Departmental Personnel Are Provided Ongoing Technical Assistance In Learning How To Optimally Transform Existing Service Models Into Desirable Personalized Support Arrangements**

It is predictably difficult for people who are used to one way of doing things to rather rapidly and proficiently shift to another. The transformations proposed in this report are such major shifts, and these will obviously proceed with higher quality, if the many people involved have available to them training and experienced "hands on" advice as to how it might be done well. The training component of this has already been addressed in this report, as it relates to the mandate of the proposed Leadership and Renewal Panel. This leaves the question of targeted technical assistance as a key unresolved matter, since its presence would have considerable strategic importance from a programmatic viewpoint. Badly implemented personalized supports help no one, and increase the likelihood of avoidable errors. This risk can be greatly minimized by connecting aspirant and novice service designers with more experienced ones both in Nova Scotia and elsewhere.

This kind of resource is rarely covered in routine program budgets as it is often "assumed" that the competency of the provider is sufficient. Such an assumption may be less risky to hold if the task at hand is a routine one that is widely mastered in the system, as individuals needful of consultation and advice can readily get it as a casual and informal element of their networking. The support proposed here is of a different order, as it can safely be assumed to be limited in availability, given the relatively modest levels of experimentation in the CBO system with flexible personalized support arrangements. Yet, if such efforts were expected to increase in scale, then the systemic advantage of obtaining useful programmatic guidance would accelerate. Its absence would pose a strategic barrier to this goal, given the probable diminished quality of implementation. This technical assistance function is also highly related to the promotion of innovation, since exposure to proven alternative advice would strengthen the ability of interested persons to reach beyond present practice.

There might be many inexpensive ways to acquire such input, so it may be more a matter of fixing the responsibility to see that it happens in some sort of orderly and thoughtful way. A key resource in this regard would be the practice that is already established in Nova Scotia of both advocates and community providers occasionally meeting and problem solving on matters of joint importance to them. Using this pattern as an inspiration of sorts, it may be possible to create mechanisms to strengthen programmatic practice, that are better tailored to ensure cross collaboration between the funders, service users and their supporters and community providers and advocates. Personalized supports are, at their essence a personal and local matter, though the sharing of experience from afar needn't be entirely local, providing it eventually reaches the grass roots where most people operate. The key point is not likely to be the means that are used, so much as that someone take responsibility for establishing a *variety of feasible strategies for technical assistance*. At the moment, this responsibility should rest with the Department of Community Services, though the actual achievement of it will have to involve the whole sector and thereby may manifest as a solution outside of government itself. For instance, in the state of Ohio, there has long existed a voluntary association that provides a form of mutual assistance, networking, training and conferencing regarding supportive living.

Though the remedy or remedies eventually selected to take up this issue may be multiple in nature it would, as a matter of clarity, be useful to imagine a service quality "center" or similar resource, to which people interested in improving things, starting something new or even evaluating what is or is not possible might get the assistance they need to proceed further. If the assistance mentioned here were qualified on matters of innovation then not only would there be more development there would also be more innovative development. At one point in Kings County, service users and their families had access to planning assistance that somewhat resembles what is proposed here. It is a useful precedent to examine. The experience for them was that such assistance was very enabling, because it helped people develop their capacity to be more effective in both imagining better, and getting some help to grapple with the many complicated issues they needed to face. Predictably, those with this assistance generally did better than without it, and the ultimate results are therefore more satisfying.

(2.9) Subsidiary Recommendation (Nine) To Major Recommendation Two: **The Department Of Community Service Should Accelerate Its Efforts To Support The Inclusion Of Persons With Disabilities Within Community Life Who Are Presently In Nova Scotia Residential Institutions**

For many years the situation of persons with disabilities has been gradually improving by way of their greater social inclusion into community life. At the same time, few people would be satisfied that the process has achieved all that is still needed. In this regard, the challenge of "well-being" for persons with disabilities ought not be reduced to simply the question of obtaining community services. After all, services are, in themselves, just the *means* to achieve something else. As has been indicated earlier in this report, this "something else" might best be encapsulated by a phrase like "getting the kind of life the person seeks and needs". It is the view of this evaluator, and countless other persons who have been close to the experience of how services actually work, that just getting a place to live cannot be the answer for many people even though they do need a place to live. Clearly, their ultimate need is more one of finding a satisfying life for themselves, and this goal ought to be given both greater prominence and relative priority in the calculation of what is important.

It is also the view of this evaluator, and the vast consensus of the field, that the best chance for people to find the life they need and seek, rests within community rather than outside of, or at the margins of community life. Yet, at the moment, there are still far too many people who are spending the vast bulk of their lives largely segregated from community, and placed in a position of involuntary compulsion to live solely with other equally marginalized persons. The most extreme example of this is the continued reliance in Nova Scotia on segregated and congregated residential institutions. The principal funder of these is the Nova Scotia Department of Community Services. Though to a far lesser degree, the Department of Health still relies quite heavily on short-term institutional care for this population, at least in comparison to some mental health systems elsewhere. The Department of Community Services is in the unenviable position of being the overseer of the much-discredited practice of enforcing involuntary segregation in institutions upon people. Clearly, as the Department itself believes, the residents of these institutions can live lives much closer to the heart of community. *The maintenance of these places constitutes a direct and persistent violation of the people's rights to be part of the community. These institutionalized persons ought to have the same chance to live in community that is now routinely available to other clients of the CBO system of the Department of Community Services.*

The Department has recognized and struggled with this contradiction, and has rather slowly moved to expand options for these most completely segregated persons. They will, nevertheless, need some political help from government to complete this job properly. There is some urgency for those institutionalized as the current pace of offering them community alternatives is so slow that many will surely not live to see the day when they can live equally and proudly amongst their fellow Nova Scotian citizens, neighbors and friends. This tragedy is entirely avoidable within the now routine state of the art "on the ground" in Nova Scotia. Thus is all the more disappointing. Many of the current residents of the CBO system were in similar situations in years past, and the continued exclusion of currently institutionalized persons from the community system should cease as quickly as is possible. Thus it is recommended that the Department of Community Services be authorized by the Province to formulate and advance a timetable for offering these persons a personalized community support arrangement that leaves them with the chance of community living *within the next five years at the extreme*.

(2.10) Subsidiary Recommendation (Ten) To Major Recommendation Two: **The Department Of Community Service Should Intensify Its Efforts To Support Home Sharing With Non Disabled Persons**

It is clearly true that advancing the extent and quality of community inclusion is a long- term matter, since what is really at issue is the behavior of the broad community. Nevertheless, the rate of progress tends to speed up when there is leadership on the issue, and when there are action strategies put in place to back up the sentiment. In the case of the Department of Community Services, this would fall into two broad categories of action. These are those related to the way supports and services are organized for people, and the way that the community is accessed and engaged by the people who receive supports.

In the first instance, the Department has the best opportunity to make advances by its abandonment of its current practice, (though not a deliberate policy), of a "de facto" reliance on the involuntary segregation and congregation of the people it funds. What this means is that people's homes can become a form of "ghetto building" where disabled service users are forced to largely live with other people who live with the same label. For the vast bulk of service users in the CBO system, there is absolutely no choice if one seeks supports, but to accept living in a home that is clearly reserved only for persons who are by definition stigmatized and excluded from more normative living arrangements. In particular, there are few options available for CBO residents to live in homes where they may elect to live with what might be thought of as "ordinary" citizens. The exception to this might be associate families but, again, they may find themselves in such arrangements involuntarily, even if not congregated with other "clients". Presently, the CBO system imposes a form of community segregation in that the residents do not have the option of living anonymously in the community like other citizens, insofar as they are restricted to "special" households reserved only for them as a marginalized sub-group of society. *It is recommended that the CBO system abandon its policy of favoring such restricted locations and arrangements, and gradually offering to current and future residents the chance to live in arrangements with people they can be part of choosing to live with.*

The people served may well choose to ultimately live with others who live with a disability, but this would be quite different from the present in that it would be a voluntary decision on their part. Today it is a non-negotiable "given" that many must live apart from the community in "special" homes. This practice can likely be substantially reduced if the person can have available living arrangements of a different sort.

The most common enactment of this shift would be to make available to people various forms of supported adult home sharing arrangements where the co-resident(s) could well be non-disabled peers, as distinct from "live-in" staff, or other involuntarily placed service users. In other instances, it might mean that some individuals prefer to live alone, or perhaps with their spouse, family or live-in companion. It is the impression of the evaluator that it is still legal in Nova Scotia for competent adults to decide whom they wish to live with. Thus, there seems no credible justification for the present discriminatory practice, within the CBO system, of streaming people into forced co-habitation with individuals whom they have no desire to live with. Further, it is also common practice for these individuals to be involuntarily moved to other homes at the will of their "keepers", and this must cease as a routine practice. If community living cannot occur within people's homes, it would not be all that surprising that it comes about so slowly outside the home. It is doubtful that this practice of segregation is intentional, as much as it is unreflective and unchallenged.

Returning to the theme established earlier in this report that "getting the kind of life the person seeks and needs" is a worthwhile goal for the CBO system, the opening up of a greater degree of social integration for people within home living situations of their choosing, will greatly reduce the enforced social isolation that often can come with being a CBO resident. It will also go a ways towards strengthening the community's perception that people with disabilities ought to have the same life options that ordinary Nova Scotians already enjoy without dispute. However, this alone would only be a beginning, as the greater challenge is for people with impairments to find their way into the broader life of the community, and find roles within community life that square with the purposes they have for their lives and the needs they have as individuals. What follows takes up this challenge.

(2.11) Subsidiary Recommendation (Eleven) To Major Recommendation Two:
The Department Of Community Service Should Intensify Its Efforts To Support The Improved Community Inclusion Of Persons With Disabilities

The state of the art in facilitating improved and deepened community engagement for formerly excluded groups is not particularly all that well developed in any jurisdiction, and it can be anticipated that progress in this regard will depend heavily on whether the matter gets the kind of attention it needs. At its root, community inclusion proceeds from very personal bases, and thus has to be seen as not simply an "external" matter of whether one is physically present in the community but, more importantly, whether one is actually involved with other people in the wide variety of relationships that are possible throughout the community. Clearly, this cannot be done without the engagement of ordinary citizens within the community. Implied in this is the forging of a myriad of personal level "mini-partnerships" with individual Nova

Scotians in the many places and within the many occasions they work, relax and socialize.

The Department can help accelerate this process at many levels, but it will need to first heighten the expectation that this goal is an important one in terms of the eventual degree to which its clients get the kind of community life they may need and want. Most people, both inside and outside the Department ardently favor this outcome but there are few distinguishable strategies being advanced to follow through on this sentiment. Again, this is not unique to Nova Scotia but it does represent a now persistent in ability to get "down to business" on this very important matter given what people need. This still leaves unanswered the question of how one achieves such an elusive, even if desirable goal.

The actual enactors of this goal will be the countless individuals who help make it happen, as a part of living ordinary community life. At its root, the key will be to stimulate and support the efforts of these individuals and small groups who may wish to make progress on these matters. *Since this can take such a variety of forms, it is recommended that the Department of Community Services, in conjunction with interested elements of the community, establish a specific long term resource to help Nova Scotians interested in community inclusion undertake initiatives that would foster progress on this goal.* It is inevitable that there would be as many initiatives as there are interested people and the key strategy is to repeatedly invite and reinforce people to get to better know and meaningfully include their fellow citizens with a disability in the many moments of community life they could come to share.

The shape of this resource is less important than that there be a focal point established for progress on the issue. Certainly, trainings, conferences and discussions of the issues involved are helpful, but these will need to be followed up with action projects, and changes in the way our communities think and act. Given the centrality of this issue to the eventual quality of community life for persons with disabilities, the Department needs to visibly support this kind of goal and to be a dependable long-term proponent and player regarding its advancement. This does not usually mean a resource within government, as the principal action is at the community level. Hence, a resource outside of government is likely to be much better positioned to get things done.

(2.12) Subsidiary Recommendation (Twelve) To Major Recommendation Two: **The Department of Community Services Should Explore Ways To Make It Possible For Individuals and Families To Share In The Financing Of Some Elements of Services**

It is often the case that individuals or families have their own funds or assets that they would like to make available or be part of their proposed support arrangements. This may vary from vehicles, property, furniture, trusts, "in kind" resources and so on. This co-mingling of resources creates many ambiguities, and it is often avoided as a result. Nonetheless, if there is to be greater service user and family involvement in support arrangements, then this area must be further clarified from what it is today. Certainly, the principle of shared or combined uses of public and private resources in the same arrangement or project, needs to be affirmed as an option, but there is also a need to address the many bureaucratic, legal, tax, oversight and other such matters that arise. Again, it is not that this is an option for everyone but it is an option for some.

Section Three: Service User And Family Influence

Observations and Comments: There Is A Need To Enable And Support Service Users And Their Families To Play A More Substantially Empowered Role In Devising Their Own Support Arrangements

The present system is largely funder and provider driven and does not presently provide or represent the full range of what service users and families might consider or design for themselves, *if they were properly supported to do so*. Part of this is due to the "bigger" structures of the Department's formal system. However, it is also true that there are not in place, and close enough to people, the kinds of philosophy and mechanisms that could deliver to "ordinary people" a reassuring measure of personal influence on the important matters close to them and their lives. It is also true that service users and their families and supporters, have a very keen interest in what services might or might not do for them, and frequently expressed the desire to be part of deciding such matters. Many such individuals were currently very much "in the dark" about what might be possible, should they have the formal option of thinking for themselves about their own priorities and needs. Similarly, many had never had significant experience with being in empowered roles, and might well not expect this or even believe that it is possible to achieve. This pattern is not untypical with formal service systems and agencies everywhere, as professionals, managers and bureaucracies tend to be afforded proportionately more control of service formation and oversight.

Nevertheless, it is important to recognize that all this can change rapidly when the underlying "rules" of the system are changed. The most important of these is to provide to service users and families the crucial delegated authority of being able to imagine what "better" might be, the ability to refuse to accept services as offered and to devise, propose and negotiate alternatives, and finally to have considerable ongoing "say so" on how supports and resources are implemented. These powers have been implicitly sketched in the section on service user influence on service financing. However, here the basis of such "empowerment" principle will be expanded more widely to other matters affecting their life. It is true that many if not most people would believe that such possibly demanding roles and responsibilities are beyond the capacity of persons with significant impairments to manage even with the assistance of their families and supporters. This stereotype is actually quite prejudicial and uninformed, as these persons have already demonstrated on a long-term basis, in both Nova Scotia and elsewhere, that they are indeed quite capable of playing a central role in their own lives. In fact, it has been almost universally discovered in attempts at person centered practice, that persons with disabilities, (as well as their families and supporters), tend to be hugely underestimated by professionals and managers as to what they are capable of being part of. Similarly, the quite real difficulties of modifying agency processes, to enable their meaningful influence, tend to be widely overstated.

It is also crucial to recognize that the capacities of people to participate more effectively in shaping their own lives and supports can be much helped if the right assistance is available. The importance of providing suitable "technical assistance" to assist people with learning to use a measure of (novel) delegated authority should never be underestimated, but usually is. It is quite conceivable that, without some sensible support, many individuals may find themselves "dumped" into situations that they are not presently well prepared to manage adaptively. Nevertheless, with appropriate support, empowered roles for service users, families and other supporters becomes eminently practical

It should also be recognized that many professionals, managers, boards, civil servants, and service users are largely unfamiliar with what would best constitute empowering partnerships. Service users, their families and their supporters, have historically been "managed" by others in the system, more so than being an independent force in themselves. Thus, it needs to be seen that the exploration of this possibility of empowered partnerships, is new territory and will involve what many call "a learning curve." Still, there are already some very instructive examples of what can be accomplished in Nova Scotia along this line, and such learning and exploration will quickly add to what has already been accomplished.

Still, all of this begins with the recognition that the present CBO system can (largely) be characterized as a system of supports that the service user "joins" or fits into. In fact, most CBO locations, service arrangements, staffing, funding, policies, practices—in short almost everything to do with the service, predates the arrival of the service user. This leaves this same person very disenfranchised from these determining decisions *from the start*. It also leaves the CBO system without the capacity to afford such a person adaptive flexibility, since most of the important decisions affecting care and support *have already been made*, and commonly institutionalized into fixed practice beforehand.

This reliance on precooked or "fixed" models of service, commonly reflects an unquestioned ethic that service design and operational decisions ought to rest principally or solely within the authority of the provider, funder, managers and professionals. The proposed sharing of such design and implementation decisions with the user of service, on a delegated authority basis, may seem to many to be inconceivable. Yet the practice experience with this in Nova Scotia and elsewhere, shows that service users and families are not at all "ordained" to be universally uninterested or incapable in such matters. In fact, this recognition has resulted in both state governments and the Robert Wood Johnson foundation in the United States collaborate in dozens of demonstration projects involving thousands of individuals throughout that country, to learn more about what is possible when "self determination" is given credence as a possibility for people. Like any grouping of people, people with disabilities vary widely in what they bring or don't bring to such possible arrangements. This is where flexibility, good judgment, and the capacity to assist such persons with these roles emerge as being important. Automatic, uniform and unchangeable supports and safeguards being imposed by bureaucracies is not what is needed here by way of support, but rather *support that is determined in regards to each individual uniquely*.

It is also worth noting that the present "personality" of the CBO system as a largely "top down", and provider agency dominated system at the delivery level, (as opposed to service users and families), very much reflects the role assigned to providers in the Homes for Special Care Act promulgated nearly a quarter century ago. The experience and thinking about what is possible for persons who live with impairments has shifted dramatically since then, as these past decades have been a time of unprecedented advances in the field. The changes that are now implied here for the role of providers and funders ought to be seen in this same light. They are simply a necessary and timely updating of practice, methods, and philosophy, in order to keep pace with the much overdue social changes in how people live with significant impairments are perceived and treated. There seems no valid reason to continue to deny these kinds of benefits to people *if they are as workable as claimed*.

While the principles like self-determination and positive presumption have a kind of abstract validity, the test is always in how they actually get put into practice. For instance, many people might be encouraged to exercise "choice" only on matters that the agency is willing to be flexible about, but the agency withholds this option or cannot conceive of it, in regards to matters that are of importance to the service user. Certainly, the service user has "choice" in this instance but clearly a quite diminished version of it. If this is combined with few instances to challenge and update the thinking of those involved in services then the collective "learning curve" is a fraction of what might otherwise be possible. For this reason service user choice and influence need to be recognized as being a constantly unfolding matter, tested everyday in practice, and not something that is achieved simply because it is officially acknowledged and several success stories are evident. A more honest and helpful casting of the matter might be that it is seen as a variable against which practice might be judged rather than an accomplishment that, once attained, is present evermore.

Observations and Comments: The Absence of Effective Partnership Arrangements With Citizens, Community and The People Served Within The CBO System

It has been observed earlier in this report, that many people both within and outside the system, feel a futility about their ability to influence either particular services or the system more generally. This is partly understandable when one looks at the present extent to which the "ownership" and control of the system rests structurally within government. Notwithstanding the recent reforms within the Department of Community Services in the direction of a degree of administrative decentralization within the Department's own structures, the CBO system is now still largely a highly centralized one, with virtually all significant decisions continuing to be made at the head office. It is no wonder that the luckless target of so much criticism of the system's stagnation are officials at head office, since this where most guiding authority is indisputably located.

Though the current decentralization reforms, (just begun in recent years), technically move budgetary and programmatic authority "down and out" to the regional administrators, the functionality in practice of this new arrangement is very difficult to evaluate. The regional administrators do not appear, at this point to be the officials taking the decisive operational decisions and responsibilities for the CBO system nor do people refer to them as holding this authority. This arrangement creates an ambiguity as to whom, in fact, is running the CBO system, as a day-to-day matter. It also clouds the question of what matters ought to rest at the head office for the CBO system, and what ought to be regionalized unambiguously. In the absence of this clarity it was almost universally perceived that the CBO system was run from head office in its entirety as it related to most crucial matters.

It should also be appreciated, but was not always done, that the authority of officials at head office is itself constrained by endless limitations that may only partially be evident at the more remote local level. Thus attributing to them some superordinate ability to solve problems, due to their (comparative) monopoly on control, is patently unfair though it may serve the need for creating a scapegoat. This perceived monopoly is certainly a problem but more because it is "structured in" by default, due to the absence of another way of managing or structuring authority.

Perhaps lost from sight is the more preliminary question of whether such an administrative reform could hope, by itself, to address the wide range of discontents that need to be taken up and resolved. It is unlikely that such a sharing of internal authority with the regions would be a panacea, since this new "split authority" might only serve to complicate the question of who can act, and to what degree of autonomy each administrative party might have relative to the other. More instructive is to notice those people who never have the use of legitimate authority. The most obvious of these are service users and their families, and the broader interested community. Their exclusion from meaningful roles in the shaping of the system is not complete, but whatever role is granted to them is restricted to largely ineffectual and disempowered roles at the individual service level, and the occasional advisory contribution. Otherwise, they remain largely spectators vis-à-vis the system, with no practically meaningful role other than that of submitting recommendations that have very little standing. *It is not at all surprising that such widespread alienation and sense of futility exists, since this is commensurate with such a pattern of distribution of power and authority.*

It is also discernible that even local and regional staff of the Department of Community Services are largely in roles of comparatively minimal authority. Their comparative powerlessness undoubtedly is conveyed to the people who approach them. It is also true that such comparative powerlessness to influence matters is common to people at this level in many bureaucratic hierarchies. The same might be said for the bulk of workers in the private service providers who are similarly bound by highly conventional patterns of "top down" hierarchies. *Thus what emerges as obvious, is the extent to which the almost unreflective use of conventional bureaucratic command and control methodologies pervades the scene.* What is at work is a culture of managing control and authority such that only the will of a small number of elite managers really counts when it comes to crucial decisions about services. Again, this factor is greatly implicated in the demoralization that also pervades the scene. *Demoralization is thus not some amorphous phenomena that appears inexplicably from nowhere, but rather is entirely understandable when people repeatedly fail to find roles where they can contribute constructively and with tangible results.*

Again, it would be quite mistaken to assume that such a pervasive and enduring culture could be authored solely by a small number of acutely clever and controlling individuals. Certainly, authoritarian and neurotically controlling individuals would have a freer hand in such a culture, but their presence might well confuse the assignment of cause and effect. This is because the same culture and structures exists to a degree both in private providers and locations in the Department in which the managers are clearly not disposed to inordinate levels of personal control. Consequently, this evaluator has been forced to conclude that, *the more compelling explanation is that people are widely unfamiliar with how decentralized authority can be created and used to the advantage of people who do not possess elite managerial status.* In fact, the ethics of organizational cultures that do operate on the premise of decentralized authority and power sharing, even with the most lowly placed service user and their families, does exist, in some small instances, within the CBO system in Nova Scotia. The largest example of this is the Service Support Group agency that has deliberately set out to resolve this issue and has largely done so. The "experimental" self management project on housing supports, hosted by the Center for Independent Living is yet another essentially successful attempt to demonstrate that a measure of meaningful authority can rest in the hands of people who are remote from the conventional hierarchies of "top down" bureaucracies. True, it is a Health Department project, but its ethics would serve equally well in any system.

These examples illustrate that, where the authentic intention exists to discover a way to empower the broader mass of people at the "bottom" of the bureaucratic hierarchies, it is quite possible to do so. This experience of achieving success with decentralized authority sharing, is widespread enough in this field and others, that there are a surprising number of instructive examples to draw upon for those seeking insight. It is also true, that in most jurisdictions power and authority still, in the main, rests mostly with the professionals and managers. Thus it is very important that experiments be attempted, on an increasingly wider basis, on how this tendency can be challenged by the evolution of other practices and organizational ethics. In all likelihood, the probable scale of success with such a strategy could be gratifying in Nova Scotia, were it to be attempted thoughtfully and with due diligence to distinguishing between better and worse versions of decentralized ways of operating. However, it is important to recall why such a strategy is needed and potentially relevant and beneficial in the first place.

As it now stands, authority over day-to-day matters does not rest with service users, families and the general citizenry to a great enough extent to justify the concept of meaningful partnership. As a result, they remain comparatively powerless within the very system that is ostensibly concerned about their well-being. The system is really not "theirs" and the locus of control has, in practice, been left in the hands of a relatively few people. This was not done by some deliberative process whereby a decision eventuated to assign authority exclusively to people well placed at the top of private and public bureaucratic hierarchies. However, as can be seen in the initial formation of the more empowering Nova Scotian examples cited here, authority was consciously organized or "structured" to leave people proportionately more in control of their lives. *This was done deliberately because of the desire to not put people in support arrangements, where control over their daily lives would be held by strangers over whom they had little influence.*

This description of the establishment of a conscious ethic of empowering service practice, at the individual programmatic level, has a further parallel at the systems level. As was indicated earlier, the Nova Scotia Department of Community Services does not yet have, (relative to the CBO system), either a demonstrably "tested and proven" strategy of decentralization or formal provisions for sharing authority at a more local/regional level with the interested community. Consequently, there can be no credible claim, at present, by the Department, to any legitimated and explicit partnership arrangement with the community. The presence of local or regional staff, by itself, merely localizes the bureaucratic work associated with a system that is essentially centralized and controlled from the top. If meaningful partnership were to be established at a local/regional level, it would require that some measure of proportionate authority sharing on a delegated basis be attempted, and sanctioned by either legislation or regulation. The most tangible expression of this would be some manner of actual community governance at the local/regional level

By "governance" it means that the essential elements of control, responsibility, financing and accountability of the local/regional system would rest with some body deliberately established for this clear overseeing and directive purpose. Advisory and consultative bodies are not the same as governance bodies as they merely provide input without any ability to act. Governance is impractical without the key elements of having authentic and sanctioned regional mandates to make authoritative decisions, the capacity to exercise proportional control over resources sufficient to direct their use and to set priorities, and some manner of community representation and oversight. It must be noted that, even delegated authority of this kind, is done at the pleasure of government, and commensurate with the legislated or regulatory intentions that form such a mandate. This is because the residual authority of elected government always trumps delegated authority, since decentralized authority derives from the overall authority of government.

As such, while authority is pushed "downward and outward" into the hands of publicly created regional governance bodies, in the interest of its better use at these levels, it is exercised subject to the ultimate oversight of government. For this reason, it would be highly incorrect to describe governance, of this kind, as "giving away" authority. On the contrary, these types of arrangements are "authority sharing" in nature. Under these "authority sharing" conditions i.e. delegated authority, a claim of partnership with the community would have credibility.

It is quite understandable that many governmental officials, (as well as those from community agencies), may well see the prospect of either ordinary citizens of the community or service users and their families having a legitimate ability to share a measure of authority with apprehension. They would undoubtedly wonder whether this authority would always be used responsibly and with wisdom. Equally, they might also speculate about whether the service user's or citizen's, (as yet unknown), ability to guide the use of resources could possibly lead to some kind of reckless spending binge. These anxieties may commonly be based on the premise that "delegated use of authority" *means the utterly unconditional use of authority by these parties,* and thus would mean giving to citizens or service users something approaching *unrestrained license.*

Such a reckless delegation of authority

is not even legally possible, except in instances where the delegating authority is acting negligently or exceeding their entrusted authority. The reason for this is in the delegation itself. *"Delegation" always means that the delegating authority essentially permits, under the same delegating authorities ongoing supervision, a conditional use of their (own delegated) authority.* The setting of these conditions by the delegator would normally provide ample opportunity and capacity to only delegate (decentralized) authority where it would be used appropriately.

The essential principle to be appreciated is that the sharing of a measure of authority with service users and their families, as well as more broadly with citizens, has been well established in countless thousands of examples of instances where both governmental and non-governmental organizations authorize any number of partnership arrangements that advance the mission of these organizations. In the field of disability there are many examples of community governance that have been in existence for a quarter century or more. Perhaps the most well known case is in Colorado, where a system of organizations called "community boards" was created legislatively to oversee each region's system. Another long-term example is the "area agency" system in New Hampshire and, to a lesser degree, the long-term but more quasi-governance area board system in North Carolina. A more recent Canadian example of this is the Alberta government's regional and provincial community governance system relative to developmental disability.

The presumption that all service users, families and citizens will inevitably abuse entrusted authority does a great disservice to the usually quite solid character of these (quite diverse) people, and the track record of their responsible conduct on both governance and advisory structures of all kinds. It also falsely presumes that, in particular instances where a given individual might be discovered to have behaved improperly, there is nothing that can be done either to prevent such conduct or correct it after the fact. It is already clear that the Nova Scotia Department of Community Services has effected, for decades, a substantial partnership with community service providers as to their delegated use of authority. *The question is why this same principle and precedent cannot* *now be more extensively and helpfully applied to service users, families and citizens.*

An often-overlooked feature of effective community involvement is the creation of a tradition of transparent and non-secret ways of operating. This is very apparent in the financial arena, where it is quite possible for budgets to be crafted, implemented and modified regionally in the full view of the public and with their involvement. Such a readily transparent system budget formation process *does not yet exist in the Nova Scotia Department of Community Services*, though there are examples of budgetary transparency in the case of the providers. This will shortly be examined. Transparency is empowering because it provides any interested party with the necessary facts to accurately assess the merit of what is going on. This enables people to act to influence events and to make authority accountable. Secrecy, as a standard way of operating, defeats or at least frustrates this capacity by concealing the true facts of a situation. Hence, the expression "sunlight is a good disinfectant", as it relates to transparency. Community governance, done well, is a considerable antidote to the exclusive access to power of both private and public bureaucratic elites, as it broadens the base of participation, makes citizens more competent and gives truth more standing. It would not be too exaggerated a claim to suggest that transparent community governance is a democratizing influence, and well within the traditions, if not upholding them, of open societies.

It would be incorrect to characterize the present practice within the Department of Community Services and many providers, of keeping many matters for internal discussion only, as necessarily being an explicit preference for secrecy. It actually reflects a common enough way of operating when there does not exist a feasible alternative. However, when useful mechanisms for transparent and participatory involvement by parties outside of the bureaucratic, are specifically provided for, then such an exclusive and inward oriented practice can be relaxed. At the same time, this type of decentralized undertaking would not be problem free, nor would it constitute a panacea. The very unfamiliarity, of all parties, with such conceivably novel arrangements would mean that these kinds of new arrangements are best approached cautiously. Poorly thought out and untested new structures of this kind might well lead to disappointments. However, this is not an argument for not proceeding as much as it is one for doing it properly.

The situation of the providers is interesting in light of the preceding, because most of them are technically guided and governed by community boards. The degree of influence these boards actually have in practice varies, as it is not uncommon that senior staff can rather come to substitute their own authority for that of their boards, unless the board asserts its prerogative of ultimate governance. Nevertheless, such a problem with how governance operates needs to be distinguished from the fact of its existence. In the case of the providers, an enduring tradition of such governance does exist and represents a major continuing reservoir of experience with community oversight and participation. It is also interesting, that despite the pervasiveness of this example of empowered community involvement and governance, that so little of its operative principles have found their way into the public part of the system. Apparently what is "good for the goose" is not as "good for the gander."

It is also interesting to note that, even with such community governance existing at the agency level, *it has not translated into empowering experiences and arrangements for either service users or their families*. This appears to be largely due to the widespread unfamiliarity of people in the agencies with alternative ways of operating their (private) bureaucracies. In the case of those agencies that are modeled after "for profit" bureaucracies and businesses, it should be noted that many businesses in the broad commercial world have amply demonstrated success with power and profit sharing. The evaluator is unaware of any profit sharing with service users being done by "for profit" providers in Nova Scotia. As such, not all business models are equal. This underlies the importance and value of creating the conditions whereby interested persons and groups can explore models of practice that leave service users with a better outcome.

Observations and Comments: Local Small Scale/"Micro" Partnerships With People To Improve Service Practice

It is notable that the more innovative examples cited here, began their efforts with a rather intense examination of interesting service user controlled demonstrations elsewhere. What resulted were concrete adaptations to Nova Scotia of practices and models pioneered elsewhere. It is also notable, in these same cases, the exploration of "best practice" has continued both internally to themselves and externally through ongoing searching for ideas and inspiration. Such is their culture of curiosity.

It is also useful to reflect on what had often been possible within the former municipal system. Despite its various shortcomings, it did provide for the persistently diligent, sufficient amounts of decentralized authority to sanction a rather routine practice of trying out all manner of personalized living arrangements, particularly under the supported apartment category. A comparable effect could be anticipated were such decentralization to be put in place in the structures of both the Nova Scotia Department of Community Services and the community agencies. However, a much larger effect would occur in instances where there existed conscious supports to innovation minded people to act on their inspirations. This would require a quite different mechanism to exist that was deliberately created to be able to foster the formation of innovative experiments. In most case this would mean a mechanism that permitted the creating "from scratch" and from the "bottom up" small demonstrations of what might be possible if one did things differently.

Initiatives of this kind are often due to inspired people, passionate about their ideas and urged on by like-minded supporters and collaborators. They often invent something that is "outside the box" and thus doesn't quite fit conventional practice. Many systems simply don't know what to do about such "misfits", and may so dampen their ardor about change that many otherwise useful impulses to improve practice are killed off before they can establish their potential worth. One easy way to do that is to have people have to endlessly and unsuccessfully go "up" into remote hierarchies to get permission to try something anomalous. They may be put off endlessly by those involved and thereby lose steam. At some point, in any system where such attempts to improve things has proven repeatedly unsuccessful, people give up and resign themselves to the immobility of the system's risk averse practice of doing nothing out of the ordinary. Certainly, given the paucity of overtly innovative examples on the scene in recent years in Nova Scotia, one has to infer that there is a systemic attitudinal block at work. i.e. it is no accident that innovation is stifled.

It would appear that a key systemic block of this kind, apart from the other lack of supports to innovation mentioned earlier, is the absence of decentralized mechanisms for establishing flexible and fresh approaches to service design and practice. Such a class of mechanisms of this kind would take the form of some system of small and even registered local initiatives whose principal purpose is to create chances to experiment or demonstrate. Even in these instances, it is useful to make several further distinctions that would refine what then could become possible. This would be the addition of the features that these initiatives could be largely autonomously governed and managed, and that their relationships with existing agencies would be that of hosted or auspiced projects.

In practical terms, these mini-initiatives or mini-projects would be under the stewardship of agencies but separated out from their internal problematic "top down" hierarchies sufficiently to operate differently enough to achieve new ground. In brief, they would have a mandate to behave differently, but on a small scale. Clearly, this would return to frustrated innovators and people concerned with the well-being of people's lives, many of the necessary tools, close at hand, to make the difference they are seeking. This would be particularly true if there were delegation to the projects of sufficient creative authority, resources and autonomy to begin meaningful participatory involvement approaches so that a better design for supports could emerge.

Goal: Strengthen The Collaborative Influence of Service User's, Family and The Public On the CBO System

(3.0) Major Recommendation Three: **The Department of Community Services Should Update Its CBO System In Regards To Service User, Family and Community Participation And Partnership**

The CBO system would be greatly enriched by the Department of Community Services taking the decision to share influence on the system with service users, families and the community. This matter may have be less important were residential supports a brief or transitory encounter. This is not the case, as they are typically very long term, and encompass so many aspects of people's lives. There also exist very real risks that obtaining services may leave the person very vulnerable to the control of their lives slipping into the hands of service providers, professionals and managers.

It is also true that the community, families and interested persons have much to offer the quality of services if they are assisted in having this contribution be welcomed and received. There seems to be ample scope within the CBO system to gradually develop this capacity at a variety of levels that should prove, over time, to be a very useful stimulus to the quality of the CBO system. What follows in subsequent broad recommendations are some of the major ways this modernization of these crucial partnerships can be undertaken. In addition to these are also a variety of recommendations throughout the report that presume this influence to be present.

(3.1) Subsidiary Recommendation (One) To Major Recommendation Three: **The Department Of Community Service Should Develop Specific Regulations**

And Policy To Assure Strong Service User and Family "Participation Rights"

This report has continuously argued for the service user and their supporters and advocates to play a more compellingly influential role in how services actually operate. This requires the formal recognition by the Department of some fundamental "rights" or entitlements, *in regards to service process*, as it relates to the capacity of services users and their allies to have standing and influence outcomes. The formal codification of these "process rights" would substantially shift the psychology and roles of the players in the CBO system.

The core "participation rights" that service users and their allies should be able to wield would be the following;

- The right to refuse to accept or protest service arrangements that they believe to be detrimental
- The right to imagine and propose what they believe to be better
- The right to negotiate changes in their service arrangements, as these are needed, in order for the service to meet their needs and preferences *as they determine this to be*
- The right to negotiate any means they see as necessary to monitor, guide, oversee and safeguard the supports they receive, including various degrees of managing these where this is practical
- The right to be fully advised of these "participation rights" and to be provided with a department sanctioned means to rectify any abridgement of these

(3.2) Subsidiary Recommendation (Two) To Major Recommendation Three: **The Department of Community Service Should Explore The Establishment Of Mandated Regional Community Governance Mechanisms**

The relationship between service users and their supporters, the interested public and the relevant officials in the Department of Community Services would be greatly strengthened if there were an effort made to establish some form(s) of community governance at the regional level. This could take a slightly different form in each region, but overall, would be characterized by the establishment in each region of a body whose task was to guide the Department on how it proceeds with community supports for the persons it serves, within the domain of long-term disability related support. This could certainly be done more narrowly only in regards to the CBO system, but this would unnecessarily restrict governance to only a reduced portion of the supports that the Department is involved with in regards to this population.

Normally, regional governance boards could be distinguished from advisory boards in that they are deliberately authorized to act on a range of matters rather than just offer advice. These non-"advice-only" matters typically include mandates to plan, set priorities, give direction and supervision to regional staff, formulate budgets, monitor quality, guide implementation and generally contribute to policy and service development thinking in the region. The reason for the provision of such an opportunity is to better link the Department's activities to the needs, priorities, and sensitivities of communities. Such bodies do not exist at the moment, and their installation would be an appropriate way to begin to repair the deficiencies that have been allowed to develop in terms of the relationship of this system with the community.

Regional governance mechanisms exist widely throughout the broad field of human services, and *properly constructed versions of these*, have proven to be effective at decentralizing authority, involving the community, improving system and service responsiveness, strengthening accountability, spurring on innovation, providing leadership and other such benefits. It is therefore all the more surprising that these are not already in place, given the long-term nature of the mission of these services. It is not particularly surprising to have found such a high level of distress within the community about their ability to work with the Department on reasonable terms. After all, the community is largely shut out from any of the usual meaningful ways that citizens influence government departments. Community governance, complete with the empowered mandates described here, is a quite feasible strategy for establishing a measure of healthy and productive relationship with the community. It is recommended that the establishment of these mechanisms should be attempted after appropriate regional consultation and collaborative planning for them with the community. These bodies could be established, for the moment, under Ministerial authority. At an appropriate point in the future, it would be advantageous to explore whether to further authorize these bodies within any new legislation that may be advanced to replace the Homes for Special Care Act.

The formation of bodies such as these should not be looked upon as a "silver bullet" way to reform public-department relationships as these mechanisms do not have any chance of repairing the relationship unless they are guided by some rather overt ethics as to what constitutes an honorable working relationship between these two elements of the system. Should these ethics fail to be developed then it can be expected that these entities will simply perpetuate the present poor relationship under a new organizational framework. It is also true that getting such a complex relationship improved under these, admittedly for Nova Scotia, still experimental conditions, will take some time and a lot of new learning. Thus the prospects look better with time if the requisite authenticity of intent prevails through the learning process.

(3.3) Subsidiary Recommendation (Three) To Major Recommendation Three: **The Department of Community Services Should Establish A New Mechanism That Would Permit Service User and Family Governed Mini-Projects To Be Established**

At the moment, service users and their supporters have to relinquish a great deal of their ability to guide and influence services simply by having their services be managed by an existing service provider. Should service users not want to face such a "take it or leave it" proposition, it is useful if providers could make available to service users the elective option of remaining more directly in charge of the supports they receive. The most obvious option in this regard would be service user "self-management". This refers to the service user directly managing some, or even all elements, of the supports arrangements that are devised. The particular elements may vary according to the service user's competencies and preferences, as well as those of the people who may be their supporters. "Self-management" does not constitute a set package of matters that are to be managed directly by the service user, but is rather a continuum of options for sharing the task of management between the provider and the service user. Since the intention of these arrangements is to strike a balance between service user needs and preferences, and the provider's need to responsibly support the individual concerned, a negotiation of the terms of the arrangement is needed between these principal parties. All matters that are important enough, will need to be agreed upon, and the fixing of specific responsibilities made with as much clarity as is possible.

This argues for the presence of a specific mechanism that would legitimate these "management sharing" arrangements, as part of the regular operational compendium of the administration of services. In effect, the principal relationship that is involved is that between the provider and the service user. Nevertheless, the Department would need to acknowledge these options as a routine part of practice, as there may be some need to prescribe some regulations as to how these might be best undertaken. At the moment, these arrangements do exist, but in relatively small numbers. With their more widespread use there may well be a need to take account of their existence in the service contracting process. Their use would very much underline the emerging reality that the Department will be a decisive factor in giving recognition to an empowered role to service users and their supporters in how support is provided.

The instance of individuals electing to have a measure of self-management is, in many ways, the simple case. A more complex option is that of where various service users and their supporters agree to form a small project to guide or oversee their supports in some collective way. If this were done as a new non-profit corporation, it is less complex because they are simply establishing a new provider. This has already been an occasional feature in the CBO system, though it has been pursued relatively rarely. In reality, many service users, not unsurprisingly, find the prospect of starting a whole new organization to be a very daunting undertaking. Nevertheless, they may still have a need to form their own projects. Consequently, a kind of "in-between" option of a "service user/family governed mini-project" offers them many of the advantages of incorporation, but without the substantial responsibilities involved.

What is meant by "consumer/family governed mini-project" is a project devised by a small group of service users or families to arrange and oversee their supports *as a group*. The service contract would remain with the involved provider, but with an arrangement whereby the project is governed by those who use it, possibly through a system of representatives or perhaps more directly. Governance, in this instance, refers to the level of overall control and direction the participants hold over their supports. In essence, the involved provider would go from being a direct manager of the project to being one where they act more as a "host" agency for the project. This permits the project to have a measure of delegated internal autonomy, within an existing corporate body, subject to some sort of mutual agreement as to what the operational relationship should look like. Not uncommonly, the host agency permits these projects to operate in ways that are distinct from the agency's more standard across the board" ways of operating. For instance, these types of projects often hire and supervise their own staff, have separate budgets and management committees, operating patterns and philosophies, distinct name, phone numbers, locations, image and so on.

Despite these advantages to the service users to selectively shape their supports, it is not all that unusual for them to prefer that the host agency carry out any number of associated administrative duties that they personally lack the interest, capacity or time to manage or steer directly. It is also useful to draw a distinction between service user "governed" projects, and service user "managed" projects. In the former, the service users guide or steer the project, whereas in the latter they are involved in actual management. In this sense, a directly managed project is more onerous for the service users or their supporters, though it allows for more detailed control and involvement. The typical project of this kind is usually run in a quite informal way if it is small. If they become large, the need for more formality becomes apparent. The size of these types of mini-projects is usually small, as the larger they get, the less the advantages to them of being hosted in comparison with starting a new agency altogether. On the whole, most service users and their supporters prefer to minimize their obligations to be involved in the detail of service delivery. Instead they typically prefer the more selective, but still influential option of governance, as composed to direct self- management. However, for those admittedly smaller numbers who want it and can manage what comes with it, direct self-management is still for them the preferred option.

Perhaps the most conventional arrangement, at present, in many jurisdictions, for service user involvement might be in their role as occasional advisers and negotiators on matters particular to themselves. This kind of arrangement does not need a particular mechanism in order to work, so much as that the service user is advised of their "participation rights" and encouraged to exercise them. Equally, the education of staff and others involved in the service to the importance and value of these rights, helps enable an atmosphere to develop wherein service user influence is just an expected part of service delivery.

The intention of this recommendation is to broaden the array of "influence" options for partnership with service users and their supporters. People vary as to their interests and capacities, and the more varied the options, the better for finding one that suits you. At the same time, with greater influence comes greater personal responsibility. Thus, those who have pioneered these more demanding roles for service users, have come to recognize that service users and their supporters may need particular types of assistance in order to perform the roles effectively. If the "empowered" options are created, but the support is lacking, it can be predicted that problems will develop as individuals find themselves unable to successfully perform their expected duties. Thus, these options are heavily dependent on service users and their supporters not being prematurely "dumped" into duties that are beyond them at the time. This requires of advisers, providers and funders a willingness to explore, and even insist on, strategies that permit the necessary "learning curves" that come with unfamiliar roles, as well as the advice, assistance and even guidance that may be needed at specific junctures. It would therefore be sensible to recognize that, while these options have many advantages, they also bring with them new perils.

One of the complaints that has arisen with the "direct payments" program in the United Kingdom where individuals with disabilities, amongst others, have obtained the right to purchase their own services, albeit in a very limited "marketplace" of options is the shear hard work and innumerable involved in "self-managed care". A similar development occurred in the Alberta experience with direct individual funding, in which individuals may have received the funding but were lacking in other ways to manage this well and were not always provided with support to achieve this. Alternatively, in instances where the individual has the support they need, often from informal "circles of support", as has often been the case with the small British Columbia "micro-board" options, the result has been more satisfactory. The Western Australian "local area coordination" system, (and now also beginning in the Australian states of Queensland, New South Wales and Victoria and currently being promoted by the Scottish Executive to local authorities in Scotland), is an instructive example of where the government not only provided people with individualized funding but also provided every person with "hands on" assistance in the form of a local area coordinator. It also provided training, technical help, the subsidy of non-service related costs associated with the individual and their family getting what they need and other timely forms of assistance. To be fair, this was done alongside a quite conventional residential service system, but it nevertheless represents a genuine and enduring, (for over a decade at present), system that has benefited thousands of people who were and wanted to be highly involved in shaping the supports they received. The important point to note is that service users and their families *were not left to fend for themselves in "empowered" situations* and thereby were helped to do much better than they might have been if isolated and unassisted.

Section Four: Innovation

Observations And Comment: The Necessity To Encourage Needed Innovation

The current CBO system is presently very well positioned to replicate existing service patterns or models. These models are not without advantage for those who live in them. Still, as has been indicated earlier, the lack of flexibility in the system to respond to a predictable variation in individual needs, comes from the specific limitation of an over reliance on standardized solutions. To create genuinely effective person-by-person solutions is not easy. "Personalized" support arrangements are not invariably effective. The capacity of any arrangement that is labeled as being "individualized" to actually be irrelevant or even harmful to the persons needs must be recognized. After all, personalized solutions can be based on false understandings of what a person might need, and thus are as capable of being damaging and neglectful as more conventional group living arrangements. (See the later section on the limits of individualized options). In fact, the widespread experience with formalized individual planning systems (e.g. I.P.P.'s, I.S.P.'s, etc.) for services...including the most recent generation of so-called "person centered" planning, reveals a rather disappointing track record of actually achieving highly relevant personalized supports. Yet there are many who equate the presence of individualization related imagery, packaging, and methodologies as being synonymous with the actuality.

One common reason contributing to a failure to individualize in practice is the rather evident inability of many practitioners, agencies and governments to "think outside the box" i.e. to innovate in direct response to individual need. While this reason is not the only contributor, it needs to be recognized for the large role it plays in predicting the eventual outcome. It should also be noted that a lack of ability to create meaningful variation in service practice, i.e. standardization of practice, is not uniform across the field, but will vary from location to location. This, of course, suggests that innovation is not a fixed or invariable phenomena, but most importantly can be influenced for better or worse.

It should also be noted that innovation is not predicted by variables such as total funds spent, formal education levels or conformity to professional judgment. On the contrary, highly innovative examples of good service practice can occur where service spending is comparable, or even less than services existing in the same economy. The fact that service innovation has already taken place in Nova Scotia, even while most other services are conventional in nature, ought to indicate that money does not fundamentally drive innovation. It is also evident that that many people who possess ample formal qualifications can be hugely conventional and rigid in their thinking and practice. In contrast, many persons with much more modest formal credentials prove to be talented, creative and inspired. Lastly, unthinking conformity to professional orthodoxies is often the hallmark of an inability to pioneer, since the act of making progress is often to break with traditional formulations.

This evaluator systematically sought out and asked repeatedly to be shown all examples of innovation that he could be directed to in the Province of Nova Scotia, as it related to CBO or related community residential services. Upon subsequently appraising what had been put forward, there existed only three examples of practice that could be considered notably innovative at the level of repeated paradigms. The crucial standard used to make this appraisal was whether the examples routinely permitted "one-of-a-kind" living arrangements to be created. It should be noted that the quite useful distinction between quality and innovation has been truncated here for purposes of brevity. The examples that emerged as significant were the Services Support Group of individualized living arrangements, the self-management project of the Department of Health, and some of the flexible supported apartment living arrangements that were originally developed by the municipal governments prior to their absorption into the Province. A fourth category that also seemed promising, but that were difficult to gauge clearly, were selected examples of supported adult home sharing with strong family influence, some of which could be included in the "associate family" category. There were other arrangements such as the home situations of the L'Arche movement, which were innovative by comparison to other approaches, but that reflected a now well-established tradition and thus were not innovative "per se." This selection is not meant to suggest that elements of existing services might not be innovative, nor that examples might exist that deserved mention, but that these were never brought to the attention of the evaluator.

. Even if the Province is replete with unrecognized innovations, it is striking that these have been kept that way. In fact, it is very remarkable that more examples were not heralded as innovative. This points somewhat to a quite desirable modesty on the part of Nova Scotians to not praise themselves. Nevertheless, something more substantive is also revealed. This is the persistent failure of the present system to produce the quite valid benefit of more widespread personalized support options being available in large numbers for service users. In fact, the self-management example owes its existence more to the Health Department, and the flexible supported apartment living arrangements owe some debt to the prior municipal governments more than the present Nova Scotia Department of Community Services and its provider network. Even the SSG example is instructive, in that its origin and growth is mostly due to the activism of service users and families, than the formal system itself. To be fair, it has been an innovation that has received funding, but not particularly in its role as a highly desirable innovation. The crucial point to recognize is that the present formal system in Nova Scotia almost assures that innovation will not happen as opposed to cultivating it. It should be noted that this does not signal that there is some official hostility to innovation at all, but rather that the CBO system is poorly oriented to producing innovations. This obviously goes beyond the government as the providers are also implicated in the low innovation rate. This pattern of rigid, inflexible, standardized service practice has been clearly well entrenched on a widespread basis for many years, and thus ought not be too readily confused with solely the behavior of today's politicians, civil servants and agency personnel as individuals. A more accurate reading of this net result is one of a critically serious and systemic programmatic stagnation in the system. This appears due to a culture of low political priority, and collective neglect of the key public interest question of what is in the best interest and well-being of the service user's i.e. Nova Scotians who live with significant impairments.

It is clearly in the interests of this population and the taxpayer that they have available to them the most sensibly responsible and affordable program options that are within the realm of practicality. The kind of individualized supports favored by the evaluator, and the mainstream of the field, have already been demonstrated as being practical in Nova Scotia, even under today's hardly ideal budgetary conditions. Thus, the deprivation of the benefit of these options to greater numbers, who would undoubtedly prefer them, must be seen as the widespread programmatic failure it is. It is a failure common to many systems that have settled into fixed ways of doing things, but is by no means necessary or inevitable. While it is true that this recognition must be balanced by the extensive and sincere commitment by both the Nova Scotia Department of Community Services and its providers to expand access to existing models of service, it would be irresponsible to not comment directly on this very central shortcoming. This ailment is all too prevalent in countless jurisdictions, and so very little at all would be gained by anyone attempting to see this as some kind of uniquely Nova

Scotian malaise. In fact, the Nova Scotia CBO system could within a few years dramatically improve its performance on innovation. A more proper way to view this stagnation is to see it as the inevitable result of a decline in investments in the evolution of the system, *particularly in those related to strengthening people to "stretch" out of current habits of thought and practice*. Complacency comes about whenever the status quo goes too long without a thorough testing of its merit, and the signs of this are now all too evident.

These signs of a lack of investment in programmatic innovations can be witnessed in a variety of obvious ways. First there has been no discernible investment by the Nova Scotia Department of Community Services, and the providers, in updating the field as to what constitutes affordable innovative practice. Secondly, there has been virtually no intentional importing to Nova Scotia of people and examples of innovation, for purposes of exposing people to interesting and useful "best practice". Thirdly, the existing innovations and innovators in Nova Scotia have received virtually no recognition for their contribution. Fourth, there has been absolutely no systematic formal invitation to the field to innovate from the Nova Scotia Department of Community Services, (in particular), but also from the non-government sector. Fifth, there exists no ongoing and systematic training/technical ("people-building") assistance to encourage useful innovations including evaluation, dissemination of original ideas and examples from Nova Scotia and elsewhere, think tanks and other such stimulants associated with the unleashing of creativity. Sixth, there is absolutely no strategy of planned experimentation. Seventh, there has been no meaningful analysis done with service users and their families as to what is lacking in the present system and what would be more preferable. Eighth, many practical suggestions have been made repeatedly over many years to the Nova Scotia Department of Community Services of proven innovations which have unfortunately ended up not being pursued e.g. personalized support arrangements. Nine, major initiatives are currently underway with no formal targets for innovation e.g. the Cole Harbour replacement. Tenth, many persons promoted to key roles in the Nova Scotia Department of Community Services and in the provider system in the last decade have had no prominent history of community service innovation and few such persons have been intentionally recruited.

This pattern must be seen in its entirety to grasp the link between these specific "counter innovation" behaviors and the resultant pervasive programmatic stagnation. The energies of the recent decade have been disproportionately channeled into systems maintenance, thereby producing the entirely predictable result of a virtually unchanged system at the programmatic and systems level (from several decades ago). This is notwithstanding the comparatively modest track record of recent times in offering some alternatives to institutional models, and an expansion in the CBO sub-system. What is remarkable is that this has occurred despite the fact that the broad field has had its most innovative years during these same past decades. In this sense, the innovative and forward moving position of Nova Scotia by the late 1970's, in pioneering community services for even the most challenging of persons to be served in the community, has gradually eroded. It is now appears at its lowest point, and will continue in this mode unless there the necessary politically led investments are made to offset this cumulative decline. It would be unfounded to link this effect solely to the apparent shortcomings of the Department of Community Services in overseeing this decline. It has also been propelled by weaknesses in the advocacy and service provider sector, as they themselves have moved from being the pioneers to now being increasingly the established system themselves. This has been combined with an aging of the existing leadership in the field in the Province, and an almost complete lack of investment in a new generation of replacement and reform minded leaders. Again, this is a not untypical pattern elsewhere in much of Canada, but this is scarcely a consolation for the service users and families who will have to personally absorb the cumulative effects of such inadequate stewardship of the future. Fortunately, such a "stall" pattern can be turned around rather quickly by a carefully considered strategy of reinvestment and modernization ...particularly if it is directed to the crucial "people building" prerequisites of change. It is unlikely that such an entrenched "investment deficit" will yield much to quick fixes or isolated and superficial bureaucratic tinkering, as the core problem is one of grass roots "people building". This type of challenge will only respond to authentic and unusually competent leadership on matters of practical service delivery, and the formal systems that would support this.

Nova Scotians will not be able to restore vitality to the current system without infusing into its private and public elements, (in this sector), some fundamentally new people and thinking. There is certainly much talent available in the Province, and a considerable desire from many quarters, including the established advocacy, bureaucratic and provider leadership, for timely advancement. This widespread sense that a crisis exists, is actually a hopeful sign, as it underlines the consensus that would be required to develop a credible rejuvenation. The possibility of expansion of services, while undoubtedly welcomed by those needing them, will not address this need for systems renewal and rejuvenation. Any expansion of service would currently just entrench the present system further, without adding anything new. What is needed in renewal is much more a creating of new life and opportunities in the system, and the provision to this sector of the kind of prominent profile and priority within the political element of government that is usually needed in order to get things moving. The investments implied here are not those of expanding services, so much as changing the approach to services to accommodate the scope of what is now practical and possible in the field.

Goal: To Establish Conditions Favorable To The Cultivation Of Innovation And Innovators

(4.0) Major Recommendation (Four): **The Department of Community Services Should Help Establish The Conditions That Will Increase The Likelihood of Innovation And The Emergence Of Innovators**

It has been argued already that the rate of useful innovation within the CBO system is much below what it is ultimately capable of achieving. It has also been noted that the essence of the remedy rests not with indiscriminately spending more money. Rather, the key is to thoughtfully develop ways to encourage new ideas to be explored and attempted. In this regard, it will be the innovative aspect of people's character that most needs stimulation and encouragement. Innovations come through "innovation mindedness", and thus the essence of the challenge revolves around the way innovators are treated by the system. The core strategies to achieve this have already been indicated by inference, but they bear repeating in the context of recommendations. The key is to see that innovation will require an ongoing investment in people and their ability to advance practice. By taking these past omissions, and inverting them into proactive strategies, they actually can serve as helpful guidelines for fostering innovation. At the risk of repetition they are used this way in what follows.

These types of people investments in programmatic innovation can be undertaken in a variety of obvious ways. First, there needs to be a distinguishable investment by the Nova Scotia Department of Community Services and the providers in updating the field as to what constitutes affordable innovative practice. Secondly, there needs to be the (carefully done) importation to Nova Scotia of people and examples of innovation for purposes of exposing people to interesting and useful "best practice". Thirdly, the existing innovations and innovators in Nova Scotia should be recognized for their contributions. Fourth, there needs to be a systematic formal invitation, on a periodic basis, to the field to proceed with needed innovations. This can come from the Nova Scotia Department of Community Services, but can be inclusive of other elements such as the non-government sector, advocates, experts etc. In essence, this would have the effect of being challenges or targets for needed innovation. Fifth, there should be ongoing and systematic training/technical ("people-building") assistance to encourage useful innovations including evaluation, dissemination of original ideas and examples from Nova Scotia and elsewhere, think tanks and other such stimulants associated with the unleashing of creativity. Some of this has been taken up by other recommendations. Sixth, there needs to be strategies of planned experimentation. It would be helped if this planning of experiments was not left to the Department, but could originate from any source that saw the potential to improve matters. In this sense, the request and mechanisms to establish innovative experiments ought to be routinized rather than being the exception that it is under current conditions.

Seventh, there should be ongoing meaningful analysis done with service users, their families, advocates and so on, as to what is lacking in the present system, and what would be more preferable. This would "anchor" the search for useful innovations in the experience of the people who rely on the system.

Eighth, many practical suggestions have been made repeatedly over many years to the Nova Scotia Department of Community Services of proven innovations which have ended up being routinely ignored. e.g. personalized support arrangements. Thus it may be useful to establish an entity external to the Department to give further credence to these sorts of proposals. If the Department itself is, at times, an obstacle to useful change, it would be worrisome to place all one's faith in remedies solely under its control. At the same time, it would be unfair to scapegoat the Department for what is a more widespread slowdown in progress. Hence, an "across the board" mechanism to promote needed innovations would be sensible.

Ninth, as indicated earlier, major initiatives are currently underway with no formal targets for innovation e.g. the Cole Harbour downsizing and replacement. This reveals what may be thought of as "lost opportunities". Put in other words, there are undoubtedly many opportunities to innovate that are contained in what may seem to be ongoing operations of the Department and the providers. For this reason, it is useful for there to be a "building in" of innovation opportunities, even in what are thought of as routine practice and systems. This represents a strategy of "testing" of the present system for areas where the performance of the system can be improved.

It is enormously useful for there to be special opportunities for emerging innovation leaders to be given scholarships and stipends to study, even briefly, areas of practice in which the field is making progress. These potential leaders can be encouraged at a young age, and may include people other than staff such as service users, families, board members, civil servants, students and so forth. At present, this may even include some expanded ties to academia, change institutes, listserves, special networks and so forth.

Tenth, many persons promoted to key roles in the Nova Scotia Department of Community Services and in provider agencies in the last decade have had no established history of *prominent and widely recognized community service innovation*, and few such persons have apparently been intentionally recruited. This remark is not intended to reflect poorly on these persons, as they bring many other needed talents, so much as it underlines *the low conscious priority that has systemically been placed on innovation*. This omission almost assures that the system will drift towards stagnation, as the presence of innovators has not been encouraged. Nonetheless, it is entirely a reversible matter if the Department and the providers more consciously tackle the issue. It should be assumed that the people of Nova Scotia do not lack the talent or will to take matters into their hands and improve their system. What will be decisive is whether they get the opportunity to do this.

(4.1) Major Subsidiary Recommendation (One): **Any Service Expansion For the Foreseeable Future Should Be Undertaken Principally Within Innovative Service Personalized Support Arrangements**

The remedy to systems stagnation will not be in a further expansion of existing patterns of services, though service expansion itself is clearly much needed. A better approach would be to initially devote more attention to investments related to the systems overall revitalization and change. This does not preclude any necessary expansion to deal with emergencies and modest growth, but it does mean that any service expansion ought to be concentrated on more innovative service initiatives rather than simply expanding conventional service models and practices. The rationale for this is that, by investing (predictably scarce) service expansion funds in innovation, it encourages the very changes the system needs in order to revitalize itself. Again, the practical significance symbolized by an increasing rate of innovation will be the very visible reassurance this gives that the system has turned a corner and is on a decidedly better track.

It is the view of this evaluator that the system needs targeted investments in order to return it to vitality. These needs compete with the very real needs for service expansion, especially in light of the many years in which a freeze has been placed on CBO service expansion. Since it would normally be difficult to find funding for both purposes, it is all the more important that these two purposes be merged as much as possible in regards to any "new" funds that may become available. It may not readily occur to many people, but another crucial source of possible funds for service expansion, is in the *re-utilization of funds already in the system, through conversion of existing service models to other patterns of services*. This strategy, already subsumed in other prior recommendations, is very difficult because it requires that existing programs be reconfigured, and this will undoubtedly discomfort many people. However, it should be appreciated that it is highly unlikely that many individuals are getting the support arrangements that are currently optimal for them, so there is great value to be had in opening up the existing services to questioning.

(4.2) Major Subsidiary Recommendation (Two): **The CBO System (Overall) Should Expand Its Degree Of Contact With Innovators Within And Outside Nova Scotia**

Though this point has already been made, it is crucial that a strong link be intentionally forged principally with innovators outside of Nova Scotia, given the comparatively small size of the Province's population. This should be complemented with similar contact within the Province and Atlantic region. It is notable from the nearby New England examples of New Hampshire, Vermont and Rhode Island, (all with similar population sizes), there has been a considerable amount of innovation and progress. The difference appears in part to be, the greater strength of their intentional links with external and internal innovators. In this regard there is no doubt at all that a significant portion of this was deliberately achieved through government strategy and policy.

This "outreach" and inquiry about good practice ought not be restricted solely to government-to-government exchanges, as provider-to-provider, advocate-to-advocate and advocate-to-provider exchanges and so forth, constitute only some of the many (mutually reinforcing) relationships that can be achieved relative to innovation and progress. Physical distance and travel costs, in the age of the Internet, no longer have to be quite the same barrier they once were. Nevertheless, such an effort does require persistence to achieve the intended reward and this will require some distinct infrastructure investments in order to succeed.

Section Five: Safeguards

Observations and Comments: The Underdevelopment of Practical "Personalized" And Other Safeguards To Ensure Service Quality, Personal Safety, and Prudent Practice

The strategy used in the creation of safeguards utilized by the Department of Community Services has historically relied almost exclusively on various approaches to minimal standards bureaucratic compliance. These minimal safeguards have principally been those of licensing, complaints investigations, training, external casework and standards creation. In the case of the CBO model, licensing has not been applied, and the standards currently in force are referred to as "interim" standards. These are somewhat anomalous, and to a considerable extent, reflect the comparatively rapid and unregulated development of the CBO system. Thus it is timely and prudent that the Department of Community Services has asked for specific evaluative comments on both its formal safeguards e.g. the interim standards, and the broader question of what is often referred to as "best practice" in regards to safeguarding its service users and programs.

The practice of creating intentional safeguards is perfectly reasonable, given that many of the people served live with considerable vulnerability, and practices that would ease these vulnerabilities are very desirable. These vulnerabilities are not at all uniform, as the needs of individuals reflect an expected diversity of possible concerns, and in quite different configurations of priority. For instance, some may be highly dependent on receiving competent medical care and thus disproportionately endangered when this fails to materialize. Similarly, others may be at great risk of having large amounts of their life and time wasted in fruitless activities and idleness, while others risk lives of stigma, social exclusion and possibly even mistreatment at the hands of those who are supposed to support them. As such, the safeguards that might most apply to particular individuals might well miss the mark in the case of persons with quite different competencies and needs.

The Nova Scotia Department of Community Services has historically taken up the issue of intentional safeguards within residential services in a quite distinct pattern. This has been characterized by a tendency to leave most safeguarding of people largely in the hands of providers. Where "external-to-the-home" and provider agency safeguards have been put in place, they have tended to be minimal in scope, formality and demands. This approach has many advantages from the perspective of avoiding a lot of invasive bureaucracy prescribing what life in people's homes ought to be. This appears not to have been by accident either, as it does reflect an authentic desire to keep home life as normative as possible. At the same time, this somewhat non-prescriptive approach tends to rely much too heavily on the strategies of minimal and uniform standards, as well as providing very little support on the question of optimal and targeted (personalized) safeguards.

This requires some further elaboration. "Minimal" standards and thresholds essentially strive to ensure that some basic level of engagement with a safeguarding related issue needs to be present if the service is to continue functioning with the authorization of the Minister. For instance, this might apply to any number of arenas such as medications, cleanliness, records, staff training and so on. On the face of it, these precautions seem sensible, even if they occasionally get implemented with reluctance, with overzealous attention to the unimportant, or with bureaucratic rigidity. Nevertheless, anyone familiar with human nature will realize that there is no way that recommended practices, even if followed correctly, are a substitute for good personal judgment. Thus sound practitioner judgment is a logical and indispensable pre-requisite of any process that is to truly ensure that defensible and dependable "duty of care" ethics are present in practitioners. This crucial human ingredient is often incorrectly presumed to widely exist, when common sense would indicate that human judgment is a far more fallible and fragile capacity than we would hope for. Formalized externally mandated "minimal" standards may create a reassuring paper symbol of prudence. Even so, they may actually be quite dangerous if they lead authorities to ignore *the centrality of the actual character of the responsible people involved in providing support relative to the safety and well-being of the vulnerable people they are meant to assist.*

Uniform or "across the board" standards have their own stark limitation of being an approach where all people to be safeguarded are treated as if they essentially share the same vulnerabilities. For instance, in some systems all staff are required to be certified for CPR training, non-violent restraints training, incident reporting and so forth, whether these are in actuality particularly pertinent or important for the specific compelling needs of the actual people in a given service. Though such a standardized and rote approach will bring about a certain nominal measure of safeguarding, it is obvious that it fails to deal with the specific worries that are present with a given individual. These specific individual safeguarding concerns may be entirely missed by lowest common denominator(i.e. minimal and uniform) standards. In this way, such uniform standards are normally calculated on the basis of what might be thought of as "shared" or "group" risks and vulnerabilities. *The "averaged" risks or vulnerabilities of collections of people clearly are not those of specific persons.*

What is needed to safeguard individuals cannot be derived from generalizations about groups. Rather, the starting point for safeguarding individuals must be the specific person concerned and the particular constellation of vulnerabilities they face. Even the relative importance of specific vulnerabilities must be understood and evaluated uniquely, if the remedies to be considered are to be relevant and potent. Thus, it is apparent that there is a quite defensible logic to the proposition that safeguards be "targeted" to particular individuals. By implication, it is almost a corollary that safeguards designed for one person might actually be irrelevant and even harmful for another. This can often be seen in small group living arrangements where the particular supervision challenges of one person have a tendency to get uniformly applied to all residents, even though it was only the conduct of one person that precipitated some restrictions. Such supervisory restrictions may well be irrelevant and even harmful to the best interests of the others. Yet these may remain in force because those in responsibility may not know or even care about the personal costs to other "innocent" persons being served alongside the offender.

As was indicated earlier, the responsibility for safeguarding individuals is systemically and principally, by "default", carried by the service provider on a day-to-day basis. It is at this level (systemically), that there exists very little thinking or policy about how such a responsibility might be carried out, quite apart from the ultimately more important question of how this might be done "optimally" rather than minimally. Optimality of safeguarding is, of course, the preferred standard, if the person concerned is a loved one. It also needs to be recognized that even once a person is "residentialized" i.e. comes under the supervision of the residential authority, the person's family still will commonly remain, in their own mind, responsible for the ultimate and optimal well-being of this person. So, the safeguarding role is conceivably one that could involve, to a large degree, the person and their family if this was recognized. This sense of familial responsibility may also exist in persons whose legal status might more be thought of as "best friend", guardian, advocate or even de facto spouse. In some instances, a given person may direct that a trusted advisor or friend play a role in specific matters e.g. estate, health or financial matters, as is commonly seen codified in various forms of partial guardianship. The key is that *this involved person has standing in a process of intentional personalized safeguarding.*

In addition to these fundamental players in a conceivable process of personal safeguarding, there are an additional range of parties that are often present in a kind of "partial" safeguarding role. The most common of these are people in external-to-the-agency casework type roles. These vary as to what they may be titled, so this role can be carried in various systems by people called service coordinators, key workers, case managers, social workers, brokers and so forth. In some systems, it is often not unheard of, that people may have several such persons assigned to them from different elements of the formal system. In the Nova Scotia case, all people are expected to have a case manager, who apparently has some manner of oversight of the given person's well-being though the extent of this responsibility is very amorphous. It is highly improbable that these people could be at all particularly effective since they can often have more than seventy-five people to somehow "oversee". Certainly, any sensible person would see the folly of relying on such a diluted safeguard for anything important given these kinds of limitations.

In the mental health case, where there exists a "split jurisdiction" between the Nova Scotia Department of Health and the Department of Community Services, the situation is even more amorphous, since the authorizing Departments for agents of this kind are different, (relative to a given individual), and the actions of one are not binding on the other. This is seen most acutely in hospital discharge planning, where there is usually no effective way to carry forward any plans or decisions taken after discharge, except on a voluntary basis. Even pretenses to some form of "clinical governance" largely are voided by the individuals transit to an entirely separate system i.e. the Department of Community Services. The same is, of course, true in reverse, though it needs to be recognized that people spend comparatively minimal time in in-patient settings, thereby hugely negating any continuity from interventions attempted there. A further instructive example of this is also evident in the present Cole Harbour deinstitutionalization pre-placement planning. Institution based professionals initially have considerable control surrounding planning for the individual and their prospective future lives in the community, even though the principal implementing authority will be entirely different i.e. community residential service providers. The possible safeguarding deficiencies of such an arrangement should be transparent to any attentive observer in that the planning taken pre-placement has no standing once the person comes under the supervision of a community provider, unless that provider understands, accepts and voluntary complies with the pre-placement plan.

Were a tragic oversight to occur in a CBO community residential setting, it may be possible in some instances to retroactively settle the question of whether the direct staff of the provider acted in a competent and responsible manner. Nevertheless, an officially designated process to intentionally create feasible and targeted individual safeguards that might have anticipated and prevented such an occurrence, simply does not exist as a routine matter in the Nova Scotia CBO system. Yet providing this is what most families and the public would expect, at a minimum, of a publicly supported system of residential care.

For the government and, in particular, the Nova Scotia Department of Community Services, it clearly will continue to be held accountable for the absence of such an assurance. This is not unique to this Department as all government agencies involved in long-term care face considerable challenges in maintaining public trust. This is invariably the case no matter what jurisdiction as it is expected that the public authorities will act with due prudence in the safekeeping of people they are to care for. It is very naïve to assume that minimal formalized "group based" safeguards will be anything but impotent, by themselves, as an effective countermeasure to the hugely diverse range of personal vulnerabilities that many thousands of residents might live with. Consequently, it is a much more secure prospect if there exist safeguards precisely targeted to individuals.

Observations and Comment: The Assurance Of Competent and Independent Personal Advocacy For Highly Vulnerable Persons

The long history of the violation of the rights, dignity and well-being of persons who live with various impairments is simply too well known by this new century to warrant undue comment. Even the most conservative of estimations of this kind of possible treatment, would reveal a patterned likelihood of this occurring at least twice the rate of what is normative for the general public. Thus it is quite responsible to ask why the intentional provision of specific advocacy countermeasures to this risk, have been systematically omitted in the instance of Nova Scotia? After all, the specific provision of advocacy and representation to protected classes is well established as a precedent at both the provincial and federal level in Canada. This absence is even more acute in the case of individuals who either have no involved family, or where they are estranged from their families. Even in the instance of persons with involved families, it cannot be assumed that the family automatically is going to provide competent advocacy. Many families are silenced by their fear of reprisal, their intimidation by managers and professionals, by their ignorance of what is rightful and possible or simply their inexperience and naiveté. It is striking in this regard, to recollect the widespread and deep suspicion many families expressed to the evaluator, about the credibility of the authorities and providers. It has been well known for some time that families, who are externally and competently assisted with their advocacy role, perform immeasurably better at this role, than they would have otherwise. Yet, at present, the right of people being served to have advocates in their life, and to have their informal advocates officially recognized as playing a legitimate and important role has not occurred. Were this to happen a significant shift would occur for the better.

It is also important to recognize just how "life controlling" residential settings can be for the people who are (usually involuntarily) placed under this control. This may be a twenty-four hour a day matter, from which many individuals may never escape. It is also true, that this control by others extends to relative strangers having enormous discretionary authority. This may even extend to the most minute and intimate details of one's existence in the home and outward from there. While such control may be used reasonably by most conscientious individuals, it is a great stretch indeed to believe that such an ethical orientation can be presumed to always be operative. The naïve presumption that prudent judgment will routinely be used in all of the thousands of momentary decisions made daily, in the context of these residential bureaucracies, is belied by the actual record. All jurisdictions suffer from a long litany of human shortcomings that eventually translate into the poor treatment of what may often be defenseless and certainly largely powerless people.

It is with this proceeding recognition that all manner of jurisdictions have seen fit to engage this vulnerability by establishing a variety of arrangements that would assure that the endangered party has unimpeded access to independent and competent advocacy. This advocacy may, in some instances, involve legal advocacy, but this (legal) element of advocacy is only one dimension of the advocacy safeguarding challenge. Much of what constitutes a person's "best interests" may not be specifically reflective of their legal representation needs alone. This why it is often family, friends and supporters who are the most present and vigorous defenders of a person's overall well-being.

At the more collective level of advocacy, the picture is more favorable in one respect. Many of the voluntary organizations that do provide a kind of class advocacy function have devoted modest amounts of private and governmental resources to nominally provide advocacy. However, these kinds of arrangements, where the party to be subjected to advocacy directly has a measure of financial control over the party allegedly providing the advocacy, is worrisome in itself Since a direct conflict of interest is created, that acts as a disincentive to "biting the hand that feeds you", such advocacy typically cannot be the kind of independent advocacy that makes the greatest difference. The usual test of the independence of advocacy is that such "structural" conflicts of interest do not exist. Where they do exist, and are allowed to persist through time, there is inevitably plausible doubt as to whether such advocacy will be as challenging as it may need on occasion to be. In the worst instances, the appearance of being "in bed" with the authorities may be insuperably difficult to put to rest.

If the concept of "best interests" is taken up fully, then the absence of forceful and independent advocacy also has a significant influence on the system it might otherwise "keep honest". The most evident sign of that would be that the system in question would tend to ignore or underemphasize the interests of service users in favor of other interests. In the case of the present Nova Scotia Department of Community Services CBO system, the source of many of the shortcomings and lack of priority mentioned in this evaluation may well be due to the fact that it has been successfully able to escape the discipline and accountability that comes with external advocacy done well. This may not be deliberate, but rather a predictable effect of the authorities, (both public and private), having large amounts of control but not being particularly answerable for its exercise. Often advocacy is only effective when the advocacy is strong enough to force or compel a response. Curiously, a well-safeguarded system that has independent advocacy, ought to be able to routinely point to a long array of decisions that resulted from direct advocacy action. Being able to point to a track record of reversals of poor practice due to advocacy, would be a testimony to the responsiveness of that system, once shortcomings come into focus.

Such an abundance of examples is simply not evident in the Nova Scotia case, even though service users and their families are quite free about their misgivings concerning the quality of support on offer. This diminished engagement of the system in routinely working through the myriad of issues that most community residential services create in the lives of those who must rely on them, would explain some percentage of the observations concerning the present programmatic "stall" associated with the CBO system. These features include the absence of varied individualized support options, the low morale of service users and families as well as progress minded professionals, the muted vitality of voluntary organizations, the absence of sponsored innovation, the lack of governmental priority and what might be called the inability to provide momentum towards renewal i.e. the perceived "stuckness" or stagnation.

To be fair, these features all would exist, to some degree, in even the best of systems. Nevertheless, a healthy system could be expected to be intensely engaged in confronting and resolving these sorts of issues. There would also be unrelenting pressures to settle the issues adaptively such that issues do not remain without remedies for any length of time. Consequently, the absence of both vigorous and independent advocacy, must be taken up as a key to both systems renewal and improvement in the life opportunities for the people who are served and those who have not yet come into service.

Observations and Comments: The Core Factor In Safeguarding People Needs To Be Recognized As Being (Strengthened) Human Judgment

It is very tempting for bureaucracies to create the impression that they are actually accomplishing something in practice when they produce documents that sound like good practice. Since these usually "say the right things" such an impression is understandable. Nevertheless, the only result that actually counts is what is actually done, as opposed to what is on paper. If human beings do not actually do what they are supposed to when it matters, it won't have helped anyone to have a written policy somewhere that says that it should have been done. Thus an uncritical reliance on external paper guidelines, goals, rhetoric, procedures and so on, would tend to suggest that human beings were somewhat akin to machines in that would always behave as they were prescribed to do. Nevertheless, most people would recognize this assumption to be exceedingly naïve, as it obliterates the insight that it is people that bring policies and procedures alive (or not).

While many people believe that it is possible to do people's thinking for them, this can lead to the dangerous reliance on habituating people to unthinking conduct. This is because their "thinking" is being accomplished by simply doing what they are told. They could conceivably lack insight into why and what is at stake even if their outward behavior was correct. Prescriptive measures that ask for and are satisfied with compliance behavior contain considerable risks if relied upon without further safeguards. However, if the prescribed goal, outcome or practice is understood as being something the adherent needs to take up thoughtfully and with judicious regard for what might prevail, then there is an increased likelihood that people will think their way through problems, rather than simply do things by rote. This exercise of reasoned judgment is absolutely crucial to the responsible care and support of people, and thus is at the foundation of any strategy of accomplishing quality and realistically safeguarding people

The Department of Community Services and the many others involved in the support of people need to recognize this fundamentality and begin to develop ways to strengthen the judgment capacities of people in responsible positions of care and support. They face hundreds of decisions about the well-being of people daily, and no written manual or set of guidelines can ever be a substitute for their personal weighing of the many factors involved in endlessly complex human situations. This is far more than just a matter of occasional trainings or consultations, as it goes to the whole question of the readiness of the workforce, and in particular human service leaders, to responsibly take up the many matters that affect the quality of life of service recipients.

This implies a crucial task of "people building", as the judgments people exercise will underlie all that is good and bad about what transpires in the CBO system. It is by strengthening the ability of people in regards to their use of judgment that much will be gained. If this factor is allowed to be ignored as to its central importance, then it is predictable that the best interests of service recipients will be endangered. If it is enhanced, there is much to look forward to.

Goal: Ensure That Highly Vulnerable Individuals Be Assured Safeguards For Their Rights And Best Interests

(5.0) Major Recommendation (Five): **The Nova Scotia Department Of Community Services Should Arrange To Provide Individuals That Need It With Independent Advocacy, Representation And Possibly Other Intentional Safeguards To Assure Their Well-Being**

At present there are many individual served in the CBO system who have the good fortune to be able to advocate for themselves as well as have available to them family, friends and other supporters to assist them to pursue their rights and best interests. In many other cases this cannot be assured. Given that these individuals are in settings and situations where they admittedly have little influence and control over what happens to them, there needs to be care taken to assure them the best possible chance to assert their rights and needs and have these acted on. These conditions are not present at the moment in the CBO system, and it is irresponsible to continue without the assurance that the many dependent and vulnerable people being served, have no one acting independently and dependably in their defense except themselves if they are able.

The normal way this deficiency has been addressed for other protected classes of people, has been to institute the means by which they can have access to independent advocacy support. In many cases this has been legal and paralegal support, but more commonly it has taken the form of individual representation by lay advocates hired for the purpose. *It is therefore recommended that such a support be instituted as immediately as possible, for the most vulnerable of individuals, and for the remainder on a gradual basis over the next three years.* It is not clear to the evaluator whether the existing Legal Aid services in the Province or the Provincial Human Rights Commission have specific involvements with given individuals at the moment, and whether there is the capacity in these bodies to respond to the scale of need contained in the CBO system. Similarly, it is not clear what independent body would best be able to support this proposed advocacy function. Thus it may be useful for a task force to be established that can look into these and other questions, and propose a prudent but effective means to assure that the individuals concerned do not have to go without competent and independent advocacy.

It is clear that the Department itself is in a grave conflict of interest if it in any way oversees advocacy that may have to be directed at itself. *Thus, an independent form of advocacy must be established that permits advocacy to occur, but leaves the Department free from a conflicted role.* It is also true that a good deal of thought should go into ensuring that the advocacy rendered is competent and of good quality. This would suggest that such proposed advocacy be periodically independently evaluated as to its quality. It also suggests that it be taken up with considerable sophistication as to the wide ranging nature of the demands on advocates who might have to respond to the full breadth of needs represented by the CBO population. It is clear that the Department of Community Services should consult widely on this matter with the community as well as people experienced with the various forms of human service advocacy.

(5.1) Subsidiary Recommendation (One) To Major Recommendation Five: **The Nova Scotia Department Of Community Services Should Officially Recognize and Give Advocacy Standing To Service Users, Their Families And Allies**

The status of friends, families and other supporters as normally being legitimate advocates for the people they are concerned with, needs to be affirmed by the Department as a "given". This status in no way presumes that the voice of such person's has any precedence whatsoever over that of the individual, but rather that their voices ought to be recognized, in their own right, as legitimate. The service user, unless otherwise denied competency status, has the right to counter these voices at will, but should not silence them. Nor should the Department or providers drive them out by inadvertently refusing to acknowledge their presence as having a legitimate claim in regards to raising whatever concerns they may have about the person's well-being.

The specific intent here is to ensure that, people who are close to people being served by the CBO system, not be discouraged from speaking up out of a sense that they have no right or standing to raise issues that may concern them. It is in the best long-term interests of people that they not be without advocacy and that the authorities bend over backwards to encourage such conduct. This strategy would add a very crucial layer of family and citizen oversight as well as add a further stimulus for improvement and progress.

(5.2) Subsidiary Recommendation (Two) To Major Recommendation Five: **The Department of Community Services Should Establish, At The Regional Level, Mechanism(s) For The Independent Community Monitoring Of The Circumstances Of People Supported By The CBO System**

At present the safeguards for the protection of persons within community homes lie largely within the system of providers and the Department. It is preferable that many of these remain in place, in one form or another, as internal safeguards. However, it is in the interest of the long-term security of people with disabilities, that they not become hostage solely to the system itself as a source of safeguards. Hence, various mechanisms should exist that encourage both the broader community, and persons close to the affected individual, to take an interest in the well-being of their neighbors who live with a disability.

Efforts of this kind would help interested people to become meaningfully involved in monitoring. It would also educate them to the needs, aspirations and vulnerabilities of people. Should such monitoring be encouraged, it would have the promise over the years of mobilizing thousands of honorable community members as potential allies and defenders. However, such citizen monitoring would not happen by accident, as it usually requires special measures designed to encourage and regularize it.

If this were linked to a form of citizen monitoring of conditions experienced by residents of CBO arrangements, (or whatever succeeds these), then there would be a formal independent means by which both the Department and providers could be independently and credibly monitored. The residents of CBO's and the public would be assured of an independent watchdog function with the goal and some capacity "to get to the bottom of things".

The precedent of citizen monitoring is well established in many fields, and has resulted in various models for doing this, ranging from individual citizen visitors, to evaluative teams, to various complaint response mechanisms, to human rights monitoring groups and so on. *It is the recommendation of this evaluator that the proposed regional citizen monitoring arrangements be established in each region, in such a way that various models of citizen monitoring could be attempted, depending on the unique capacities of the regions to undertake these. Consequently, a uniform system need not be developed in favor of a region-by-region approach. Nevertheless, whatever is developed should be able to operate with independence, be able to make public its findings as appropriate, and foster the mobilization and education of the broader community as potential allies for the residents.*

The most obvious beginning to this would be for both providers and the Department of Community Services to welcome the informal but effective monitoring of the well-being of loved ones by families, friends and other supporters. This needn't be enacted in any formal way but their status as a desirable, legitimate and fundamental, (if not "core") safeguard, would be very helpful. It is usually people who are closest to people who are the first to notice and act when people are imperiled on even small matters. Consequently, keeping these people at a distance is counterproductive. "Rules" governing their presence seem less helpful, than simply having a published principle that affirms their presence as a highly practical way to make people that much more secure in terms of their well-being.

(5.3) Subsidiary Recommendation (Three) To Major Recommendation Five: **The Department Of Community Services Should Establish A Mechanism So That Crucial Personalized Intentional Safeguards Can Be Negotiated And Enacted For And By Individuals Who May Need These**

At the moment, at the individual level, there are many safeguards formulated and acted upon to reduce hazards and advance positive aspects of the lives of specific persons. These are both *intentional* and *informal* in nature and probably go a long way to making people's lives less vulnerable to any number of worrisome developments. These safeguards may be initiated by the individuals themselves, or by their families and supporters, interested staff and professionals, the funder, or anyone else who is concerned and involved. Such conscientious activity is very hard to prescribe or even demand, since so much of it depends on the good sense, caring and practicality of the people involved. Nevertheless, the expectation for, capacity for and quality of the safeguarding that does go on could be very much helped by supportive training and problem-solving. Other variants on this type of this assistance have already been recommended elsewhere in this report. What has not been taken up is that there is not now in place a specific mechanism to negotiate intentional individualized safeguards to be put in place *formally.* In particular, there is no mechanism for the establishment of formal intentional personalized safeguards agreements between the Department, providers and the affected person and their supporters.

There may exist some vulnerabilities that an individual has, that are of such an acute and serious sort, that it is simply not prudent to leave the matter to chance. Under these conditions, it is only reasonable that concerned people might formally ask that this vulnerability be officially recognized, that specific safeguards to counter this be developed, and responsibility assigned for assuring the enactment of any agreed upon safeguards. This could then be formalized as a recorded safeguarding agreement between the involved parties *if this was thought to be helpful.*

It is recommended that a "people friendly" mechanism be established, at the grass roots level, for concerned people to formulate, enact, assign responsibility for, and record the kinds of personalized safeguards they believe would be helpful for the well-being of the residents of the CBO system. This mechanism should be reserved only for matters that are of such gravity that the absence of intentional safeguards could be life threatening, damaging to the long-term well-being of the person, protective of public safety or the safety of the individual, or fundamental to the person's rights. It would be pointless and create too much unnecessary bureaucracy for every minor concern to have to be dealt with in such a fashion, and thus it should be unmistakably clear that such a device should be reserved only for the most serious concerns.

It is conceivable that honorable people could well disagree on what many situations may require in order to protect the well-being of the person. Thus, it must be anticipated that agreement may not be readily obtained on many matters. Since the mechanism proposed here is *entirely voluntary* in nature, the resolution of such disputes will have to rest with an agreement where the parties "agree to disagree" and record this for posterity. Should the neglect of a matter be so worrisome to an involved party, that they feel it to be unconscionable to leave matters as such, they should have available to them the right to advocate for further action. The Department ought not to have the obligation to sanction the content of each of these proposed agreements, but it should promote the exploration of useful safeguards for particular individuals as conditions warrant. *The mechanism proposed here is novel to the system, and thus its* *implementation should be on a trial basis, with the experience evaluated once it has been in use for a sufficient period of time to establish its merits and problems.*

(5.4) Subsidiary Recommendation (Four) To Major Recommendation Five: **The Department Of Community Services Should Install A Specific Safeguard To Resolve The Ambiguity Of Who Is Directly Responsible In The Case Of Individuals Who Need Supervision To Prevent Them Being Harmed Or Harming Others**

At present it is not clear who is responsible for the percentage of individuals in the CBO system who either are at great risk of being harmed by others or harming others. It is the judgment of this evaluator, *that the present system of case management, as presently configured, does not constitute a dependable safeguard for this purpose.* After all, these persons often have seventy-five people or more that they must follow. Even if they concentrated only on the people who were most worrisome, their ability to be available on a twenty-four hour basis is simply not present. At best, these roles should be renamed as client resource workers, (for the most part), as that sort of task is all that they could manage with any sense of realistic hope of success. They simply do not have the time to undertake the kind of intensive, and often urgent, problem solving that safeguarding of this more serious kind would involve.

There is also not a system in place within the CBO system that would serve to identify individuals who pose a risk of the kind described here. As a result, all individuals are treated equally, in that there does not exist a "specialized" supervision system for the people who might merit it. This kind of specialized safeguard would only be possible if there were a system in place to identify the individuals that merit the highest priority for supervision. Consequently, the secondary task of assigning responsibility for the supervision cannot be undertaken. Under these conditions of ambiguity, the providers have no choice but to assume that it is they that will be held responsible, should a failure to supervise occur.

The ambiguity is therefore more around the extent to which the Department of Community Services has simply left this responsibility with the provider to manage as best they can, or whether they intend to play a practical role and to what extent. This is a common dilemma when funders and providers share responsibility for people's lives, and it is rarely an easy matter to ultimately resolve with clarity. If the belief is that the Department's case management system assures this supervision, then the individuals concerned are in jeopardy, as has been indicated already, given the inadequacy of this system to carry out this task. *It is the view and recommendation of this evaluator that the provider clearly be identified as providing the principal day-to-day supervision of individuals with this high priority need for supervision.* However, it should be established by the Department that the provider is competent, ready and willing to carry this out. Providers that believe that they cannot assure the proper support of individuals should have an obligation to make this determination as clearly as possible and to advise the Department of Community Services promptly. Such an explicit agreement about high priority supervision arrangements would greatly lessen the ambiguity that is currently present as to who must do what to ensure a given person's well-being.

What is needed is that the Department put forward the necessary system to establish this selection and vetting process of providers, formalize the ways to make an assignment of this supervision priority, and develop with the provider the specialized supports that would be sufficient to safeguard the individual concerned. The intention here is not to make all supervision subject to such an advanced "screen", but simply dealing forthrightly, on an obligated proactive basis, with the relatively rare instances of individuals whose situations are the most precarious and worrisome. The presumption should be that extraordinary care regarding supervision may be needed in regards to at least some individuals, and that the means to achieve it needs to be institutionalized. At the same time, the assignment of this identity to individuals should be only done with great care and deliberation, and the individuals concerned should have priority in being assigned advocates to safeguard their rights and interests. It is also true that considerable care should be taken to preserve the privacy and discretion with which such matters are taken up. It goes without saying, that providers unwilling to undertake such supervision, for whatever reason, should have the right to decline involvement.

(5.5) Subsidiary Recommendation (Five) To Major Recommendation Five: **The Department Of Community Service Should Recognize The Validity Of Individuals Preferring To Voluntarily Live In Intentional Communities, Seek Lives Of Relative Reclusiveness Or Live In Households With Distinct Cultural, Religious Or Ethnic Identities**

While the trend towards increased social inclusion is generally beneficial for the individuals involved, it would be unwise to not recognize that there may be instances where at least some individuals, would freely elect to temporarily, partially or otherwise limit the degree to which they choose to be involved in their communities. While the number of these people may be relatively insignificant overall, there may be occasions where they wish to exercise the prerogative to either withdraw somewhat from the community or largely operate in a sub-community with its own religious, ethnic, linguistic, dietary, cultural or other distinctiveness. It is certainly not true that all intentional communities favor some manner of reclusion, but some certainly do.

Similarly, there exist individuals who prefer a lifestyle of some degree of reclusiveness or distinct lifestyle who might, nonetheless, still have need of supports. In both cases, the Department will need to recognize that such a choice, freely undertaken, be one that has to be accepted as valid for purposes of qualifying for community support. This in no way prohibits the offering to such persons of any number of more socially inclusive alternatives, nor would it limit the Department's capacity to monitor the well-being of the person receiving supports.

It is recommended that the Department of Community Services adopt a policy for the delivery of community supports, that both acknowledges and affirms the desirability of individuals having unimpeded access to community life, but that also recognizes that some individuals may, on a considered basis, voluntarily choose to limit the extent to which they elect to pursue the advantages community inclusion might bring them, as well as seek to be part of a distinct subculture. It is true that in this decision, as well as many others, that the Department recognize its obligation to ensure that individuals have access to support, be freed from coercion and be properly informed of their options. If these conditions are met, and the relative reclusiveness will not imperil the person, this choice should be respected. It is often the case, that during periods of mental disorder, individuals may elect to undertake actions that they wouldn't if "well". Nevertheless, the legal mechanism's to ascertain whether an individual has the necessary competency to act in their best interests are already in place, and therefore there is no need to add to these.

Section Six: The "Interim Standards" Of The CBO System

Observations and Comments: Regarding The Present "Interim Standards" Of The CBO System

The Interim Standards of the Department are principally oriented to ensuring that the homes themselves are safe and comfortable for the residents. In this they are largely concerned with site or facility issues. They tend to mostly ignore the question of the supports the person receives, and the competency of the provider to deliver the supports to the person(s) served. What essentially needs to be approved in the Guidelines is the home and its functional capacities. In almost all cases, these standards are minimal in nature, prescriptive of mandatory practices, substantially oriented to paper compliance, and largely ignore quality achievement and enhancement. Consequently, it is important to consider what they do, or do not, contribute to the CBO system.

The Guidelines do not, in any way assist with the question of whether the person is in the right or proper living arrangement given their needs. This function is partly carried by the classification system but only to a very minor degree. The Interim Guidelines do assure that people be assessed for eligibility and suitability prior to placement in the home, but the conduct of this is not covered by the guidelines. Neither do the Guidelines speak to the adequacy, relevance and quality of supports, once they are resident in a CBO. As such, the well-being of people is confined to some rather broad procedural practices, e.g. monitoring arrangements, documentation etc., that essentially avoid the question of whether the service, as configured, is the right arrangement for the person.

The Guidelines do prescribe some compulsory uniform safeguards for several hazards or concerns that might affect people, such as the possibility of fires, abuse, persons needing CPR, keeping adequate records etc. There is no effort made to differentiate whether these are more or less worrisome for a particular person, i.e. they are general, uniform, "across the board" safeguards, and are not at all targeted to particular vulnerabilities of given individuals. i.e. they are applied indiscriminately, as if the concerns behind them were entirely applicable to all people without exception. They are "blanket" safeguards, and are concerned with only a limited number of the possible vulnerabilities of the people served. In many instances, all they ask for is written policies of the provider to apparently demonstrate that the underlying concern is noted by them, even if the policy has no effect in practice.

The Guidelines require of providers some minimal behaviors they must comply with, but do not essentially deal with the actual competence of providers other than being able to comply with these rather general, formalistic and somewhat organizationally focused concerns. They essentially cannot discriminate between a superior and inferior provider, in any way, as they are oriented to basic qualifying compliance of the provider's on-site practices in order to be eligible to be funded.

This raises the question of what the point of having such guidelines is. It appears that all they accomplish is to assure that only a small number of largely trivial quality related matters are addressed relevant to a given individuals well-being e.g. access to clean linens, access to a toilet, not sleeping below ground level, having a minimal sized room, adequate drawer space, no foul odors in the place etc. One wonders why the providers are presumed to be so potentially incompetent and injudicious that the Department has to compel that these commonsense decencies be observed. If the assumption is that providers need to be told that people need clean linens or whatever, why in the world is the funder using such negligent providers in the first place? Would it not be better to establish a rather more stringent test of essential fundamental qualification of providers so that the Department does not have to resort to prescribing such inadequate "minimums" in such a "paint by numbers" unthinking compliance manner?

It is also true that the "home related minimums" seem to be a creditable attempt by the Department to assure that the actual homes of people are not disgracefully inadequate. However, the same question again arises as to why are providers being used that would do this sort of thing in the first place? It would seem that the better starting point would not be the promulgation of Guidelines of this kind, but rather the taking of a decision that the focus of regulatory interest should be the providers capacities to responsibly manage their duties, given the trust placed in them.

(6.0) Recommendation One: The Present System To License Homes Should Be Replaced With A System To License Service Providers

Since it is the providers that are more fundamental to the care and support of people than the homes themselves, then it is these organizations that should get the most intense scrutiny. The homes are those of the residents and ought to be of good quality, but it is the providers that must assure their suitability. This is particularly the case as it relates to the present pattern, where the homes are essentially "provider houses", as opposed to those of the residents. In time, the homes ought to increasingly become the "private" space of the residents, as is the case with ordinary citizens. This will become much easier as the resident,(and their families and supporters), moves more and more into the role of being the people who actually select, rent and own the home. Support, and the providers involved in assuring it, could gradually become separate from the question of housing, as the resident, (and their allies), move more into the role of control of their homes.

It should be noted that the goal of assuring that the homes are not deplorable, remains meritorious and should not be abandoned whatsoever. However, this should be taken up much more in the context of homes being the homes of the people served. Were this to be done, then the person as well as the supporting agency should both be held accountable for the home and its condition.

The type of license to be issued to providers ought to be a license that establishes a rigorous review of provider competencies and funder expectations. Given what has been recommended in this report overall, the qualifications needed for providers of supports would generally have to address these broad areas of concern;

- ☐ Provider understanding of, and capacity to assure, that provider staff exercise responsible personal judgment in terms of what is often called "duty of care" i.e. responsible support and supervision the of the people's interests and well-being that they support.

- ☐ Familiarity with desirable practice and principles regarding how service users and their families and supporters prefer to be treated i.e. "right relationship" principles

- Familiarity with generally recommended practice and principles regarding service design, operation and quality as it relates to supporting people proficiently in the community

- Familiarity with strategies that enable the resident's home to be a "real home" i.e. "their's"

- Familiarity with commonly recommended safeguards to ensure that the health, safety and proper supervision and supports to those who need them are in place.

- Capacity to manage normative administrative and financial matters.

- Familiarity with the rights of the people being supported and the ways that these can be violated through mistreatment, indifference, neglect, abuse etc.

Such a shift from licensing places to licensing providers is a significant change, and the formulation of the mechanism to do this should be developed with considerable consultation with the providers and service users, families and advocates. In general, it would be desirable to have such licensing be a status that had to be renewed every three years. The provider organization should be formerly audited at this point to assess its capacity to comply with broad guidelines as to provider capacity and capability. These proposed guidelines for providers should be designed so as to answer the question of whether the provider can or cannot do its job responsibly. *Licensing would be contingent on the provider's ability to meet the test of fundamental fitness to undertake the role* .In some jurisdictions, providers need to pre-qualify in order to be eligible to bid on service contracts. Licensing, as described here, constitutes pre-qualification in that without it the provider would lose all contracts automatically. The grounds for that kind of ultimate sanction, given the criteria already mentioned, would be the following;

- ☐ Persistent poor judgment regarding responsible care.
- ☐ Failure to relate appropriately to service users and families.
- ☐ Failure to responsibly support people in the community as a recurring as opposed to anomalous condition.
- ☐ Failure to assure the people served the "common sense" necessities of home life.
- ☐ Failure to provide feasible safeguards for the health, safety and the physical security of residents.
- ☐ Persistent administrative, financial or organizational failure.
- ☐ Failure to protect residents from abuse, mistreatment or neglect.

(6.1) Recommendation Two: **The Specification And Monitoring Of The Quality Of Supports Should Be Largely Taken Up As Part Of Service Contracting Rather Than Licensing**

The quality of a provider's work should be taken up principally as a performance related contractual matter, rather than a licensing matter, and on a year-by-year basis. Quality, in this sense, ought to be addressed as the extent to which the person is relevantly supported, and whether this is done at a consistently proficient level. The daily monitoring of providers, (by the funder), should not be done through licensing, but rather as part of ongoing service contracting. The provider's performance with its service obligations ought to be a much more rigorous test than that of the simple permission to be a provider that licensing provides. At present, the portion of the Interim Guidelines that relates to minimal health and safety concerns, would be usefully redone as criteria for assessing provider capacity. This ought to also be done in regards to administrative and financial matters, and can include sections on written policies and practices where these need be explicit and uniform. All other requirements regarding the household itself, ought to be a matter of service contracting, and involve the articulation of the service user's concerns about the household itself. These matters are entirely too diverse and specific to a particular individual to be reduced to some kind of "across the board" requirements. It is also true that the Province must be quite scrupulous in ensuring that its desire and obligation to protect people, not get translated into a mandate for a kind of unintentional "bureaucratic home invasiveness". This constitutes yet another reason to move regulatory interest away from the homes of people, to the organizations supporting that home.

Under this proposed arrangement providers, as well as residents, ought to have the right to register concerns with the funder that relate to the quality of the homes and home lives of the people served. Normally these sorts of concerns can lend themselves to agreements, of a voluntary nature, between the parties that resolve any issues that may be present. These voluntary agreements can ultimately become written attachments to service performance and contracting obligations regarding particular households or individuals, if the parties insist on such a formal step. The point here is to tackle quality matters on a person-by-person, and household-by-household basis, rather than trying to create some sort of overarching uniform standard for all individuals and households. This shift of quality concerns to the contracting domain, *and to a level much closer to the person*, helps to link quality back to people in a very direct and individualized way.

This proposed arrangement brings service users and families more directly into the decision-making on the quality and adequacy of supports. It also reinforces the principle that providers *do not control* a person's home, but are only "guests" in their home, and thus serve at the pleasure of the residents. This is only possible if the funder formally recognizes this proposed status of the service user, their family, supporters and advocates in regards to the service contracting process. At present they are excluded from the contracting process, and this practice of neglecting and "de-chaining" the people served, from key service design and practice decisions, should cease.

(6.2) Recommendation Three: An Updated Version Of The "Consensus" Guidelines Should Serve As The "Interim Guidelines" Until The New Proposed Licensing System Is Put Into Place

It is recommended that until these kinds of arrangements can be put in place, that the Department should use the "Consensus Guidelines" previously developed by the community and submitted to government some time ago. These reflect the conscientious work of many people and agencies, and represent a higher degree of rigorousness than do the more dated "Interim Guidelines". It is important that the Department show respect for the consensus these represent, even if there are arguable details in them that it would disagree with. Even these "Consensus Guidelines seem overly bureaucratic rather than incisive but they nevertheless represent the best starting point. It would seem very possible that these "Consensus Guidelines" could be amended relatively quickly in an updating sense. Authorizing these would then free people to begin working collaboratively on the new system proposed here.

(6.3) Recommendation Four: There Should Be Developed A Set Of Desirable Outcomes For Service Users As A Key Ingredient Of The Proposed Quality Contracting System

The Department of Community Services should not have any particular difficulty establishing an audit system for providers suitable for establishing whether they can competently and responsibly support service recipients. The health and safety, administrative and financial and other concerns taken up in the present "Interim Guidelines", could simply be reworked and placed into the audit process. What is not present in any form is a set of good descriptors of the kinds of personal outcomes for people that should be used as goals for good service quality. These are increasingly common in the field, and provide a valuable set of reference points in discussing quality both for individuals and more broadly. The most prominent example of these sorts of outcomes would be those developed by the US Based Council On Leadership And Quality.

These were originally developed for their private accreditation system but are increasingly reflecting a shift from organizationally focused auditing to using service user experience as more centrally the measure of a good service. There are many other examples of "outcomes" around as well. Such outcomes would be helpful as a beginning point for both contracting and service development discussions. *Nevertheless, it should be recognized that the use of these could quickly become meaningless if the threshold for their achievement is set too low.*

Section Seven: Important Matters Specific To The Mental Health Portion Of The CBO System

Observations and Comments: The CBO System Is Currently Better Organized For And Responsive To Persons With Disabilities Than For People With Mental Health Impairments

The CBO system "works" on an overall basis much more favorably for persons with disabilities. This seems, in part, due to a "net" preference and priority in terms of who gets served, being with people with intellectual and physical impairments. This is not to say that persons with mental health difficulties are not served by the CBO system; it is that it *appears* that they are not being provided, on a proportional basis, with appropriate and coordinated resources under the current arrangement. It was not possible for this evaluator to statistically verify this possibility though such an exercise would be useful. *It is of* *great significance that there does not exist a single mental health (coordinated) community support system solely dedicated to the needs of persons with mental disorders*. This is evident, on the one hand, in the rather limited residential options available to them as a group (as can be judged on a comparative basis), and on the other, the lack of a targeted and functioning joint program for them *between* the Nova Scotia Department of Community Services and the Nova Scotia Department of Health. In all likelihood, this also reflects the comparative strength of the constituencies advocating for community supports.

It was not possible for the evaluator to establish that there was a unintentional net bias against persons with mental disorders in terms of the use of available resources. However, it was not possible to disprove this possibility either. What was clear was that the present arrangement "divides" the responsibility to assure this kind of equity between several government authorities. The source of this difficulty appears to stem from the split jurisdiction of community mental health services between the Nova Scotia Department of Community Services and the Nova Scotia Department of Health. This problematic arrangement has existed in a troublesome unresolved state for decades, with virtually no basic change in the core of the problem.

This "core" problem is the need for persons with mental disorders to have as "seamless" a system of community support as can be arranged. By tolerating a system wherein authority, resources, and implementation are divided, it almost assures that those to be served will find themselves in an endless "run-around" between Departments and systems. If the acutely low priority and profile of persons with mental disorders is added to the mix it is a recipe for a lack of focused progress.

Any number of "internal-to-government" voluntary coordination mechanisms have been attempted over the years, with the net result being the largely dysfunctional arrangement currently in place. The ultimate resolution of this matter has never materialized and will require a political decision to resolve. The essential service delivery issue that is created is that persons with mental disorders have far fewer choices within the CBO system. They have also have found it hard to get into the CBO system both directly from the community, and coming from inpatient units under the control of the Nova Scotia Department of Health. This is particularly notable since the funding moratorium on CBO arrangements has been in place.

One key unintentional advantage that has come from this arrangement has been that persons with mental health disorders have had to rely much more heavily on largely low cost supervised apartment living arrangements. In the process, they have ended up with support arrangements that are typically much less restrictive, more personalized and flexible than other kinds of CBO arrangements have proven to be. The previous system, involving municipal governments in the delivery of services, resulted in some municipalities proving to be very astute and ingenious at supporting and managing such "improvised" support arrangements. These arrangements still exist today, though the municipal culture that produced them has now been subsumed in the Department Of Community Services.

It is highly unlikely that the present "split" system will result in persons with mental disorders getting what they need. Their situations will always suffer from the ambiguity that comes when two government departments cannot resolve who ought to do what. Even with much good faith in evidence at a lot of levels, it is nonetheless a recipe for bureaucratic paralysis. When policy, budgets, authority, accountability and strategy are ambiguously divided across two jurisdictions, it should not surprise anyone that decisions, focus and progress prove to be elusive. The fact that such a situation has persisted for some time is not merely due to bureaucratic issues, it also reflects the deep inherent difficulty with the substance of trying to figure out the best way to respond to mental illness. Though people with mental disorders no longer spend much of their lives in health controlled residential settings e.g. psychiatric hospitals, there has long been a preference by many to assign overall direction of mental health matters to medical personnel. At the same time, much of what people with mental disorders actually need, for most of their hours of the day, falls outside of most health services e.g. work, education, housing, social life, rights, income etc.

A fledgling mental health community supports system exists within the Health system at the community level, but major areas of the needs of such people are handled elsewhere in government e.g. employment, housing, income supports etc. In contrast, people with other disabilities tend to be less "split" in terms of their needs across government Departments. Acute psychiatric inpatient care has still tended to dominate the contact of service users with the Health system, at least in regard to mental health matters. This pattern would seem to suggest that the "main" system that people with mental health disorders rely on is the community system. This system is the one now overseen by the Department of Community Services.

Yet, what is obviously true is that it largely has no "treatment" authority whatsoever, as this is in the Health Department. Service users require access to both community supports and treatment and it would be preferable that these be guided by the same authority if they are to be one rather than two systems. This could be achieved by selecting one of three governance options. The first would be to move all community supports to the Health Department. The second would be to move mental health community supports that are in the Health Department into the Department of Community Services. The last would be to create a special mental health "sub-department", either placed under the control of either the Minister for Community Services or the Minister for Health, or perhaps jointly administered under both their authority, but as a single system. This could perhaps take the form of a Mental Health Commission.

Observations and Comments: The Poverty of Individuals Vastly Limits The Adequacy Of Their Housing

The complaint was often expressed to the evaluator that many individuals on highly limited fixed incomes believe they are forced for economic reasons to take housing that was deplorable. Often it was referred to as "slum housing". This seemed particularly true for people with mental disorders who tended to be over represented in the supervised apartment aspect of the CBO system. This risk of limited housing choices did not appear to hold true for the group living and associate family components of the CBO system. These seemed to have, in effect, a "de facto" rental subsidy available to the persons served.

Consequently, a somewhat inequitable situation exists where some arrangements within the CBO model tend to favor one sub group of people served in residential care, as it relates to the housing portion of the total residential cost of support for a given individual. It could also be argued that this same comparative spending advantage exists in relation to the other costs of care, on an overall basis, though the fullness of evidence needed to make the case would require a study beyond the scope of this review.

The effect of their poverty on persons who fall into this category of involuntary "slum housing" users is not easily teased out, but it is widely recognized that poor housing has many perverse psychological and health effects. A recent study on this by the effects of providing decent housing to people, (A Drop In The Ocean, Health and Social Policy Research Center, University of Brighton, 2000), showed a sevenfold improvement in measurable beneficial health effects. It is all the more worrisome that the people who most reported this experience were mentally disordered persons. These are persons who disproportionately survive with only the relatively minimal supports offered through the supported apartment living arrangements.

At one time under the former municipal system, a rental subsidy was part of the service, but this is now not as customary though it continues to be part of some people's supports. It is a relief that the prospect of a "slum housing" problem is largely absent for most CBO residents, but it is a grave shortcoming that it remains such an apparent problem for persons with mental health disorders.

Goal: Persons With Mental Disorders Should Be Provided With As "Seamless" As Possible System of Community Supports As Is Possible

(7.0) Major Recommendation (Seven): **The Department of Community Services And The Department of Health Should Resolve The Creation Of A Single Community System To Serve Persons With Mental Disorders Within Two Years**

As has been indicated earlier, persons with mental disorders should have in place a single system to address the majority of their community service needs including housing, employment, transport, income and so forth. The key features of such a system would be that it would be under a single administering body, that it include the majority of the community supports that people with mental disorders rely on to make their lives in the community, that would permit the long-term planning and development of needed community supports, and that would allow for the adoption of best practice in the field, the empowerment of service users and their supporters, and that would provide the necessary protections and safeguards for the rights and safety of these individuals in the community.

The matter is not as simple as either placing such a community system entirely within the Department of Community Services or Department of Health, as there is also the question of whether either Department would be adequately able to meet the need. The matter might best be resolved by the establishment of a separate Mental Health Commission to operate such a community system. It is the view of this evaluator that such a question is well beyond the scope of this review to resolve. It is clear, however, that the decision has been deferred too long and it would be extremely timely to have the Province finally resolve it after the paralysis that has come from leaving it to the bureaucracies to resolve. A political decision needs to be made as promptly as is wise. The internal government mechanism to do so has not been specified by this evaluator. What would be most credible would be the assignment of this task to some entity, removed from the bureaucratic interests involved, that had the independence to recommend a remedy that is in the best interests of persons with mental disorders.

(7.1) Subsidiary Recommendation (One) To Major Recommendation Seven: The Nova Scotia Department of Community Services And The Department of Health Should Establish A Mandated Joint Working Party To Prepare The Background Data Needed To Proceed With Recommendation Seven

At present, there has not been an attempt to assess the amount of resources both Departments are currently spending overall on mental health supports in the community. Any plan to investigate a "seamless" community supports system will have to grapple with whether it is actually programmatically and fiscally possible to achieve this, quite apart from the legal and bureaucratic matters involved. It is important for planning purposes that this be done. This goes well beyond expenditures on residential supports as persons rely on both systems for a variety of their life requirements in the community.

(7.2) Subsidiary Recommendation (Two) To Major Recommendation Seven: The Department of Community Services And The Department of Health Need To Restructure The Fiscal Incentives Regarding Community Placement

The present arrangement between the two Departments has resulted in two major shortcomings that affect the recipient of services. The first is that, when a person who is currently living in a CBO goes into a psychiatric in-patient unit with the Health Department, the Department of Community Services still has to fund the now vacant space of the person while they are in hospital. If they are unable to do this for a lengthy period while the individual is in hospital, then the person will lose their home. The reason for this is that the Department of Community Services cannot afford to fund empty spaces indefinitely, and therefore has to set some point where the person is no longer a resident. While it is true that many larger providers use their own funds to cushion this effect to a degree, the problem nevertheless remains. This effect thereby renders people unnecessarily homeless, and denies them the continuity of abode that most reasonable people would see as sensible.

The second problem relates to the difficulty that occurs when persons who have not historically been part of the CBO system, try to access the system while in placement in the psychiatric unit. Such persons are "unfunded" persons for the Department of Community Services, and therefore may not have priority relative to other persons seeking services. The Department of Health, understandably insisting on their prompt placement from hospital, may not realize that the Department of Community Services may not see the person as a funding priority, given the budget it has to work with. After all, there does not exist a line item for Health related community placements in the Community Service budget. Consequently, the Health Department may spend upwards of over a thousand dollars a day waiting for a community placement that may actually cost a small percentage of that cost to the taxpayer, were it available. The individual may wait unnecessarily, inappropriately and indefinitely for a community placement to materialize. They may also, out of desperation, be forced to take whatever is available, even if this is unsuitable for them. These problems could be resolved to a great degree if the Department of Health and the Department of Community Services shifted the present community placement financing arrangements. *The first recommendation would be for the Department of Health to absorb the per diem costs of individuals coming from CBO living arrangements that involve hospitalizations of more than 60 days.* This would provide continuity of support in the community for the person to return to, provide incentives to the Health Department to limit expensive hospital stays, and provide the individual with the certainty of leaving hospital promptly.

In the case of the instance where the person in hospital has no funding priority with the Department of Community Services, the problem could be resolved in one or both of the following ways. *The first would be to have the Department of Health and the Department of Community Services prepare a joint estimate and account each fiscal year, of the number of people expected to fall into this category.* They would then annually create a special account that would be jointly administered by the two Departments to pay for either preventive supports to inhibit hospital placements, or long term "after hospital" supports. This would either be a precursor to the "seamless" community supports system for mentally disordered persons, or a useful ongoing mechanism to manage this quite solvable problem.

Another mechanism that might work *would be for the Department of Health to agree that it would pay 100% of the initial community placement costs for an individual who has never been served by the Department of Community Services, for a period of six months after hospital discharge. For the subsequent six months, the two Departments would share these costs at 50% each.* This would assure rapid placement from hospital and the eventual accelerated long-term priority of the individual for Department of Community Service funding. This could conceivably be merged with the prior recommendation depending on how well these numbers of people can be correctly predicted on an annual basis. Therefore an experimental attempt to try this proposed arrangement should be considered.

(7.3) Subsidiary Recommendation (Three) For Major Recommendation Seven: **There Should Be Established Between The Department Of Community Services A Joint Mechanism For Ensuring That High Risk Individuals Are Properly Identified And Safeguarded**

There are, at any point in time, individuals who will require very targeted support and supervision, particularly when the person circulates between hospital and the community. This transition opens up a very significant vulnerability as to who is taking ultimate responsibility for the person's support and supervision, *once they are in the community*. In many instances this may not be a pertinent concern, as the individual needs nothing more than routine support. The difficulty arises when the person presents the unmistakable possibility of being a source of harm to themselves or others but does not need a hospital stay.

While there are certainly competency issues that enter into these situations, these should not distract the system *from unambiguously pinning down who falls into the category of needing a very high priority in regards to support and supervision*. Further, it also needs to be established, as unmistakably as possible, who is the responsible party for ensuring such supervision and support. Lastly, where this support is clearly not in place, there needs to be a way in which the person's situation can be officially declared as intensely worrisome so that immediate decisions can be made to correct this. This proposed mechanism is yet another key element in the "seamless" community system being considered here for persons with mental disorders. This is consistent with recommendations elsewhere in this report regarding the targeting of persons needed high priority community support.

(7.4) Subsidiary Recommendation (Four) For Major Recommendation Seven:
The Department of Community Services Should Establish A Rental Subsidy Program That Reduces The Likelihood Of Its CBO Service Users Having To Use Poor Housing

It is a decidedly difficult task to draw the line as to what constitutes the kind of housing that many people with mental health disorders claim to be the "slum housing" that they believe they are being forced to live in. Nonetheless, given the widespread evidence of this pattern throughout North America of poor people with mental disorders disproportionately occupying the least desirable housing that is available, it would be prudent to assume that some version of this exists in Nova Scotia.

It is well known that adequate rental subsidies, particularly of the flexible and portable variety, go a long way to reduce the use of inferior housing by any group who has access to them. These have been present in the Nova Scotia scene for many years, so are not at all an entirely new proposition administratively. Nevertheless, if they are only available on a limited basis, their overall impact is predictably muted. What is recommended here is that the number and adequacy of these be expanded and targeted to individuals with the least desirable housing with a special emphasis on the most poor of people with mental health disorders.

Major Recommendations Concerning The General Priority And Strategy Of Implementation Of These Recommendations

The recommendations contained in this report are long term in nature, in the sense that the achievement of the goals associated with their intentions cannot be expected to occur rapidly. It is also true that the recommendations contained here are likely to prove to be very difficult to implement, particularly since they will mean a quite noticeably different system and way of operating than has been customary for the several decades that the essential elements of the CBO system have been developing. These recommendations are very much outside some key aspects of the "culture" of the present system, and thus ought to be considered to be challenging from the perspective of what has been conventional thus far. Nevertheless, the actual practices which are recommended are not at all impractical or outside the mainstream of good practice in the broad field. In fact the bulk of them would hardly be considered controversial.

It is quite normal for evaluators to recommend changes that the recipient cannot or will not proceed with. This response from those being evaluated is not necessarily a sign that the recipient disagrees with the intent or detail of the recommendations, *as there are many constraints of all kinds that face authorities that do not face evaluators*. Thus, what is also needed is advice as to what, amongst the many recommendations, would be the most decisive to act upon early, and what might be matters that could be deferred initially. The answer to this depends upon the observer, and their own appraisal of matters, but certainly it is incumbent on those offering advice to also guide the recipient as to the relative importance and fundamentality of the recommendations.

It is recommended, therefore, that five major decisions be taken in regards to this report. The first is that the general directions of the report be endorsed in principle, principally by the government of the day. This is crucial for purposes of acknowledging the very real advantages this report holds for the many people with disabilities who hope for a better life for themselves in the years ahead. The second is that the Department of Community Services acknowledge the deep need for renewal and revitalization of the system by appointing the proposed Leadership and Renewal Panel.

Thirdly, the Department should make a commitment to pioneer, on a limited basis, the flexible service arrangements and advocacy strengthening efforts, especially for the most vulnerable and endangered, as proposed here in this report. Fourth, the Department should commit itself to the core innovation, judgment, empowerment and leadership "people building" investments that will be so enduringly invaluable to what then becomes possible in the future. Lastly, that the Department resolves to settle the split jurisdiction question concerning persons with mental heath disorders. Were these decisions key decisions to be taken early in the process, it would set the stage for all of the other recommendations to be eventually tackled.

There is one overall factor that, nonetheless, underlies the future capacity to make progress with as challenging a set of directions as have been presented here. This is the recognition that he leadership needed to achieve these is of a quite different sort than has been normal in the CBO system. The features of a new generation of leaders that would be commensurate with ambitions such as are contained here, are as follows;

- Ability to "partner" with the community and, in particular, service users and their supporters

- Advanced ability to work with empowered service users and their supporters in the crafting of "bottom up", up-to-date, flexible, personalized and affordable community supports

- Ability to convert traditional services into more up to date ones

- Ability to create the conditions for innovation under difficult and persistent conditions of low governmental priority, interest and funding

- Rigorousness about safeguarding and supporting difficult to serve people within overstretched community services

- Ability to create widespread confidence in the system and its strategies

- Ability to make the kind of crucial "people building" investments that will turn the tide over time

These leadership qualities should not be seen as just being needed by individuals "at the top", as that would be counter to the "leadership from the grass roots" thrust of this report. Much of the needed leadership should be assumed to exist at "lower" levels of the system, as this evaluator found ample evidence of it, at least in terms of its potential if encouraged. In fact, a good amount of it rests outside of the "paid" portion of the system i.e. within the community, and in the people who rely on services. The task will be to recognize this potential and to gradually encourage its expression. Nevertheless, there will still be a need for leadership "at the top of" the Department, the provider organizations and the advocacy groups, which have often been a crucial stimulant to progress. In fact, this is where the initial leadership is most needed. If these were to unite on common goals and resolve to persevere together, then there is every reason to believe that the trust placed in them will be deserved. It is the hope of this evaluator that such a needed "coming together", is advanced by the Department and community leaders, as it will be the crucial catalyst that is needed.

A Brief Comparison Of The Nova Scotia CBO System To Other Jurisdictions

It is almost a maxim that people want to know how they are doing, and the case of the Nova Scotia system is no different in this regard. The Department of Community Services, the commissioners of this evaluation, have asked for some sense of context, as to where the CBO system "fits". The question is deceptively simple, and yet it is actually very difficult to make such comparisons, given the huge diversity that exists, even within a given jurisdiction. All jurisdictions contain within them various sorts of anomalous patterns that limit the use of easy generalizations. Yet, it is often possible to make valid descriptive and evaluative statements that do not do a disservice to these important nuances.

The development of a special tool to "rate" the Nova Scotia CBO system against other systems, in a standardized, previously validated and easily accessible manner does not presently exist. However, it is possible for the evaluator to comment on various dimensions of service and give a perspective on where Nova Scotia "fits" relative to other jurisdictions. To facilitate this eighteen variables are presented here along with brief commentary on each. Further, each will be contrasted with other jurisdictions with the simple categorization of (A) above average or notably positive, (T) typical of most places and (P) problematic or deficient. A serious limitation of this kind of measure is that it tends to rate variables in relation to the field in general, rather than to the best the field is accomplishing at the moment. This kind of (normative) measure is not particularly useful if the field is itself doing an unremarkable job with an issue.

Eighteen variables have been selected here that largely cover matters taken up in the narrative of the report. These are broken into the three broad categories of System Performance Features, Individual Quality Related Features and Safeguarding Features. The "reference group" of jurisdictions selected for comparison are Canada, the United States, the United Kingdom, Australia and

New Zealand, as these are the jurisdictions that the evaluator knows best and are readily accessible in English for people from the CBO system.

Category: Individual Quality Related Features:

Feature One: The Quality Of Social Inclusion Of Service Users: Rating (Typical)

Comment: This is an issue that the field (overall) is not doing particularly well at, despite the longstanding goal of community living. There are many good examples to the contrary in almost all jurisdictions including Nova Scotia. Nova Scotia is typical in not doing anything specifically to improve its performance on this item. One senses that the Nova Scotia CBO system does not fully harness the generous side of Nova Scotian communities in its focus. It is quite common that many positive examples do not get attention because they seem so "ordinary". There are certainly many "success stories" heard from other jurisdictions but one has to wonder whether what is distinctive is just that these are being celebrated more than that they are doing better overall.

Feature Two: Smallness/Personalization Of Settings: Rating (Typical) to (Above Average)

Comment: The CBO system is notable for its keeping living arrangements small, and for sticking to the maximum grouping of three people in a single site. This is not as unusual as it used to be, but is worth crediting. If the whole Nova Scotia community residential system were taken into account this feature would drop into the "typical" category given the (still remaining) large community sites in the community system, but outside the CBO system. There are certainly a percentage of jurisdictions with very low numbers of people living together, but Nova Scotia would be notable for being so systematic about keeping numbers small.

Feature Three: Individualization of Supports: Rating (Typical):

Comment: The theoretical potential of the Nova Scotia CBO system to more thoroughly individualize its options is quite substantial. At present, its efforts in this regard are very typical of most jurisdictions, in that its forward momentum is slowing or stalled, given what is actually possible. This will be a pivotal decision in regards to what the future holds. The practical mechanisms and policies for accelerating the growth of these options need development in the CBO case but this would hold true in the vast majority of systems. As indicated earlier, the place of the CBO system relative to other systems could quickly improve but it would require less reliance on group living models. A "typical" rating in this regard means that the CBO system could usefully borrow some ideas and examples from other selected locations.

Feature Four: Flexibility of Supports: Rating (Typical)
Comment: The CBO system is much too settled into rather standardized ways of offering of services, without much incentive or invitation to experiment with unconventional remedies. Its lack of efforts to identify the "next generation" of service improvement is typical of many jurisdictions in which services have become routinized in concept and implementation. Nevertheless, the CBO system could do very well on this item were its latent flexibility accentuated in the coming years. This is partly a problem of vision and a willingness to create a lot of latitude to experiment with anomalous arrangements. To be fair, there are jurisdictions that have many flexible examples, but this may have more to do with the provider system than the government system alone.

Feature Five: Service User/Family Empowerment: Rating (Typical)
Comment: Though the amount of service user/family empowerment in the CBO system is very problematic from an overall quality point of view, it is quite typical of the practice in the field of excluding service users and families from meaningful influence regarding the services they receive. Nova Scotia does have some fine examples that show that this lack is unnecessary. Other jurisdictions are actually much worse than the CBO system, because of the size of the services, the

agencies and the bureaucracies that come with them. "Smallness" is a real advantage to empowerment, and Nova Scotia could very much exploit this for good effect.

Feature Six: Service User/Family Innovation Assistance: Rating Typical To (Problematic)

Comment: Given the hugely curious nature of the many service users and families that the evaluator contacted it was surprising to see so little done to develop an innovation minded partnership with such persons. Most jurisdictions have at least some resources and focus placed on assisting service users and families to "imagine better". The CBO system has cooperated with at least some innovations, but needs to do this routinely rather than as a rare exception. The most innovative jurisdictions tend to externalize such assistance in order to give service users the benefit of independent advice. Consequently, this assistance may actually rest outside government itself, and commonly enough, in service user, advocacy and other grass roots sorts of groups. In some cases it may be found in special Institutes or resources. The UAP system in the United States is one such example. Another would be groups such as the Empowerment Resource Centers in the US, the Scottish Human Services Trust, the Community Resource Unit in Queensland, Australia and so forth.

Category: Overall Systems Related Features

Feature Seven: Returning People From Institutions: Rating (Typical) To (Problematic)

Comment: If one looks at the recent "Trends and Milestones" Data Summaries in Mental Retardation, February 1999, as a sample comparison from the US institutions, there were only a third of the people left remaining in them in 1998 that were there in 1977. This trend was even more pronounced in New England where three states had no institutions left (RI, VT and NH), Maine had only twenty left to place, and Massachusetts had dropped from 3,401 to 1379 residents. In this regard, the 1990's have shown a much slower pace of offering people community living possibilities in Nova Scotia than the overall rate of a nearby US region during roughly the same period e.g. ratios US/ME 1987-1998 (15:1), CT (2:1), NH (185:1), VT (194:1), RI (300:1), MA (2:1) in contrast to the Nova Scotia rate (NS 1985-2002 estimated 2:1). The Nova Scotia figures seem more typical of the some of the slower Canadian rates in the 1990's.

Feature Eight: Cost Of Service: Rating (Typical) To (Problematic)
Comment: The per capita spending levels in Nova Scotia for community supports were quite economic, in the sense that there appeared to be little waste that was detectable in the aggregate. On the down side, it also reflects very weak infrastructure investments, due to overall political and financial neglect of the system. Improved spending levels alone would not ameliorate matters, unless there is investment directed towards system improvement and modernization. It does reflect well on the CBO system that it has done as well as it has with the resources it has been given. Nonetheless, it is capable of being much more creative even with the resources it has. In this regard, though, it has lots of company, hence its similarity to most systems.

Feature Nine: Avoidance Of Unnecessary Bureaucratization: Rating (Above Average)
Comment: Almost everywhere one goes today one heard complaints about the invasiveness, burdensomeness and sheer irritation of having to deal with bureaucratic systems requirements. This reflects the increasing technocratic nature of human service management. The Nova Scotia CBO system appears to have been spared a great deal of this, perhaps as an unexpected benefit of a long period of poor funding. There certainly is no conscious policy in this regard, though this would be enormously helpful in converting what is largely a serendipitous factor into a more conscious one.

Feature Ten: Focus On/ Investments In Innovation: Rating: (Typical) To (Problematic)
Comment: As indicated elsewhere, the field seems to have slowed its rate of innovation in the 1990's. Progress is still being made in many locations, including Nova Scotia, though the general pattern is worrisome. Innovation is much more "people" related than it is "dollar" related, as it derives from what one does with what one actually has in hand. The CBO system has no conscious strategy of innovation, at present, though Nova Scotians are clearly quite as capable of being innovative as any other group. This is particularly true in their trait of not relying on the idea that more money will alone solve all problems.

Feature Eleven: Leadership Investments: Rating (Typical) To (Problematic)
Comment: The evaluator was not able to identify an explicit leadership development initiative of any kind in the CBO system. There were leaders and potential leaders present, but no conscious effort to cultivate and harness their abilities. It was also noticeable how isolated the CBO leadership were from leaders in the broader field. This is a key infrastructure investment that many jurisdictions either ignore or do not recognize the importance of. Nonetheless, the best systems do see the value of this even though their specific investments may be labeled something more innocuous than "leadership" they may still have the same effect.

Feature Twelve: Quality Related Education: Rating: (Typical) To (Problematic)
Comment: Human services are hugely labor intensive and the quality of the "paid" and "unpaid" workforce is highly related to whether they are equipped and supported to do what is asked of them. The recent efforts to improve minimal training levels have been taken up on the belief that this is true. However, simply expanding conventional training, particularly of a minimal standards variety, will not address the core catalyst questions of what gets people to excel, and to go beyond routine scripted responses. In this sense, "excellence" education most certainly involves a struggle with expanding the values and vision that get people

to do the remarkable. Nova Scotia is not alone in not engaging this issue of non-minimal quality. Nevertheless, its resources devoted to this subject are very minimal in comparison.

Category: Safeguarding Features

Feature Thirteen: Education/Protection/Enforcement Of Rights: Rating (Problematic)
Comment: While it would be incorrect to construe that people in the CBO system have their rights violated at a rate that is worrisome, it is also not possible to feel assured that their rights are well safeguarded. Given their vulnerability, the absence of even a minimal program to educate, protect and enforce rights is not reassuring. Many programs intended to do this can prove to be expensive and ineffectual in the end. Human rights flow ultimately, not from systems put in place to highlight them, so much as the actual attitudes of people that are present in a given culture. The CBO "culture", if there is such a thing, has nothing (formal) of this kind at work to create, enable and support the most helpful attitudes and conduct. These days, that deficiency stands out relative to most jurisdictions.

Feature Fourteen: Supported Family and Community Involvement: Rating (Typical) To (Problematic)
Comment: It is generally recognized, in open societies, that citizen and family involvement serves as a kind of "watchdog", advocacy and catalyst safeguard. This can occur at many levels. In the CBO system it is virtually not a feature of the formal public system though, informally, it is generally heeded if asserted. The picture is better in the provider sector, due to the citizen governance feature. The CBO system is not alone, however, in having weak partnerships with families and the community. Nonetheless, the CBO system is virtually devoid of even the weak but ongoing advisory structures common to most jurisdictions.

Feature Fifteen: Access To Independent Advocacy: Rating: (Problematic) To (Typical)

Comment: The present CBO system has not yet taken any systematic measures to ensure that its service users have access to independent advocacy. This practice was once more associated with the US system, but is now increasingly normative in Canada, Australia and the United Kingdom, amongst others. Given that many of the people the CBO system supports are amongst the most vulnerable of Nova Scotian citizens to being mistreated this omission is remarkable. The Canadian jurisdictions are comparatively weak in this regard, in comparison to other countries, and Nova Scotia falls within this pattern, much as the Atlantic region does generally in regards to independent advocacy. National governments are generally more supportive of advocacy than are state and provincial governments, (or local authorities in the UK).

Feature Sixteen: External And Independent Monitoring And Evaluation: Rating: (Typical) To (Problematic)

Comment: It is common in many systems to have available various ways of monitoring services and what is happening to people in them. The effectiveness of these vary, but the best combine both formal and informal monitoring and evaluation of services. The CBO system has considerable potential to develop these, particularly in regards to sharing this function with the community, but has not done so this far. In reality, there is little rigorous and scheduled independent monitoring or evaluation of a formal sort in the CBO system, leaving just (unorganized) informal monitoring. To be fair, a lot of the expensive formal evaluation systems in other jurisdictions do not seem to have changed life all that much better for the service user. Consequently, formal evaluation is more meaningful if something is done with what it produces.

Feature Seventeen: Supports To Individual Judgment and Decision-making: Rating: (Typical)

Comment: The basis of so much that keeps people well and safe rests with the countless daily decisions of people entrusted with some aspect of personal support. Supporting this feature of service and human functioning is a key safeguard. The CBO system itself only cursorily takes this issue on, though the providers do as a routine part of their duties. The supports available to people who wish to improve on this item are very scarce in the CBO, as well as other systems. Nevertheless, the absence of ample ongoing in-service training is most notable in the CBO system with predictable consequences. The availability of consultation seems almost nonexistent.

Feature Eighteen: Targeted Supports For "High Risk" Individuals: Rating (Typical)

Comment: The CBO system, to its credit, serves many individuals who would be considered "high risk" due to one or another feature of their needs or conduct. It does this without drawing undue attention to these persons. Nevertheless, it could benefit from being more effective in identifying who is most at risk and what would be most helpful to ensure their security and well-being, without losing the many advantages of keeping these persons from being stigmatized. All community systems are struggling with the needs of these individuals, and the CBO system, with its limited resources and investments in this aspect of service, is also struggling.

Summary: The CBO System In The Context Of Practices In Other Jurisdictions

The CBO system would be instantly recognizable to people in other jurisdictions as sharing many of the same essential features and challenges as their systems. It has taken on the task of serving the wide assortment of people in the community who turn to the system for assistance, and has served them at a comparatively reasonably low cost overall, with an emphasis on getting people services above all else, even at the expense of the system itself. It has done less well *than the better systems* in getting people out of institutions, providing people with safeguards, innovations related to developing the next generation of services, formal safeguards and, in particular activities of an educational/ consultative sort. In short, its infrastructure for providing services is now highly depleted, though this is not due to administrative waste, but rather lack of long-term political priority and spending.

Part of this gradual depletion has been due to a lack of effective community advocacy, and high-level political and fiscal commitment to continuously modernize the system. Were the CBO system to make the crucial leadership and innovation related investments towards more updated "person centered" services, in cooperation with family and the public, the Nova Scotia CBO system could emerge in five to ten years time as one of the more notable systems in North America. As has been indicated many times, getting this result is essentially a "people performance" problem less than a fiscal one. Thus, *its accomplishment will be very dependent on the people harnessed to achieve it.* As it stands now, it simply does not have the reservoir of talent or resource "infrastructure" to do very much beyond trying to serve as many people as possible with what it has. A rebuilding of people capacity must be attempted as the foremost precondition for achieving what is envisioned in this report.

The Limits And Vulnerabilities Of Individualized Support Arrangements

This report has very decidedly emphasized the advantages of flexible individualized supports, as a core strategy, of responding to the unique needs of persons. It would be dangerous and irresponsible to advocate for these without also providing some precautionary warnings of the risks associated with practices of this kind. What follows is a brief attempt to do so.

The Possibility of Irrelevant But Nonetheless Individualized Supports

Though it is rarely intended that individualized supports be only partially or wholly relevant to the actual needs of a given person, it is quite possible that the supports are badly conceived at the outset. There may be any number of contributors to such an outcome, but they would all likely derive from one of ten common and recurring "core" errors. These are the errors of,

- Not properly and deeply understanding the person being supported and their actual needs
- Not caring to understand the person sufficiently to deeply and correctly understand their needs
- Uncritical reliance on, and faith in, habitual or overvalued ways of supporting people i.e. "fixed" models and practices, as well as panaceas
- Attempting to meet the needs of other parties or interests at the expense of the person
- Utilization of incorrect assumptions or theories about what people might actually need, thereby leading to false steps
- Misjudging the relative degree of fundamentality of what needs are most important or crucial, relative to other needs
- Paying attention to only some of the needs of the person
- Confusion of the relative priority of the needs and wants of the person relative to some responsible standard of "best interests"

- ☐ Failure to give authoritative standing to the person and people close to him or her who know the person well and are authentically committed to the person

- ☐ There are insufficient external safeguards put in place that could reliably discern crucial irrelevance and thereby challenge the possibly faulty design decisions

These errors are usually undertaken by well motivated and generally honorable people, so even good people with very good intentions can be present in situations which end up producing supports that prove to be irrelevant and even harmful to a person. For this reason it is best that people look beyond the people involved in designing supports to the actual support decisions and the inherent merit of these.

It is also very important to consider the prospect that calling something "individualized", "person centered" or whatever other term is used to denote its apparent value to the intended person, does not at all mean that it is, just that someone believes it to be so. Consequently, it is useful to consider that such undesirable outcomes as neglect, harm, indifference, and even degradation can be and are routinely "individualized" as is the damage done by them to the affected person. Ironically, many such harmed persons usually have in place a bureaucratically sanctioned personalized plan that adamantly asserts that the person's unique needs will be paramount.

Otherwise Valid Supports Are Not Implemented Properly

It would not be all that unusual for people to "drop the ball" when it comes to implementation. This can come about whenever there are multiple people involved who do not share the same understanding of the person and what needs to be done. It can come about simply due to flawed communication and the intervening effects of the service system itself. Thus, it is very useful to start from the premise that all implementation of supports, even those of an informal nature, are vulnerable to error, breakdown and even perversity. As a consequence, the agile and perceptive organizer of supports would hold to a set of disciplines that enabled implementation errors to be discovered and corrected as early as is possible. Even better, errors are foreseen and preventively dealt with before they have any effect.

It is useful to examine implementation from the vantage point of the various aspects of putting things in place that "must" occur properly. If these "musts" are undertaken well then much of what is important has been addressed. Therefore it is useful for people interested in the "doing" to keep the following points in mind as they struggle with their responsibilities. The ones that follow, while not exhaustive, cover much of what commonly can get poorly addressed in the implementation of individualized supports.

- A "right relationship" or ethical partnership is established and maintained with person to be served and their allies and supporters

- There is clarity about who is responsible for doing what, and the responsible person accepts their duties or roles

- The "right" people are selected for the task

- There is a capacity in place to easily change the support arrangements as might be needed

- The attitudes and values that are crucial to the day to day decisions are constantly scrutinized for their quality

- There is clear designation of overall quality leadership responsibility even if this is shared in some collective way

- There is substantial attention paid to the persons well-being and circumstances at all times i.e. they do not get "lost" or forgotten in the process

- The interests, motives, behaviors and thinking of all the "vested interests" involved are constantly evaluated in terms of their effect on the person's well-being

- There is a struggle to ensure that an overall "coherency" and balance of considerations of the different aspects of implementation occurs relative to the person

- There is adequate attention given to the renewal of the supports situation, such that the person does not settle into a custodial routine and existence

The task of "walking the walk" is so easy to underestimate in terms of the many difficulties involved. It is likely that even the very best practitioners are constantly enmeshed in dilemmas and limitations that greatly strain their ability to get things right. In fact, it is surely one sign of probable impending poor judgment and incompetence when key people become too complacent. The very best tend to have a more humble view of their abilities to keep things in good order, as they are aware of and respectful of the endless fragility of what is, after all, *human* service.

Perhaps a key source of eventual problems with implementation stems from the failure to properly appreciate how very hard it is to really understand someone and to support them optimally. Given that many people may not really be sure about what or who they are, it should not come as a surprise that others may well miss crucial things. On the other hand, it is also important to recognize that much can be done that is highly useful if the effort is carried through over time. Time offers the great advantages of people being able to get to know people and achieving the trust that comes with passing the tests that lead to "peace of mind".

The Realities Of Personal and Community Life Even When Being Supported Well In Individualized Arrangements

Life goes on, even when much of what a person needs is on hand. Persons who are largely satisfied with the supports they are getting may still, nonetheless, struggle with the many aspects of life that others also have to contend with. This would normally include living on a budget, wanting, making and keeping relationships, finding and sustaining one's interests, facing hardships and losses, making mistakes, bearing up with responsibilities, facing difficult choices, making sense of one's life, getting one's life in balance and so on. These are normal, and often tedious, aspects of personal life that are mixed in with the many joys and pleasures of life.

Persons who live with a disability share these aspects of life, as well as the further task of having to face whatever may come with the absence, quality or manageability of the supports they receive. Additionally, they may do this in the context of a community that may misunderstand or even fear them, reject involvement with them, look down upon them and so on. None of these difficulties are entirely avoided, even when one receives reasonably sensible and ample individual supports. Nevertheless, they are to a significant degree less burdensome, if one has the security and satisfaction of getting the assistance and support one needs in a suitable way.

It is also true that individualized supports may actually create some problems for the person that might not have occurred quite in the same way in more conventional services. This might include any of the following, (as well as many others);

- Onerous and overwhelming responsibilities for managing their own supports
- Extreme personal social isolation even though one is in a "place of one's own"
- Difficulties in finding and evolving one's identity
- Vulnerability to predatory interests in the community
- Chances of being "lost sight of" because one's life is now "out of sight"
- High discontinuity due to the unrelieved rotation of casual and itinerant staff
- Insecurity relative to the uncertain dependability and quality of service agencies, bureaucracies, professionals and managers
- Expanded freedom and choice without much support in managing it

Yes, it is still desirable to have flexible personalized supports available for people. Nevertheless, these are, at best, just an aspect of what constitutes getting and keeping a good life for oneself, even if they are important. For this reason it is best to undertake the provision of personalized support arrangements with the same wariness that many now feel towards "conventional" services. The state of the art may be changing but much of life remains as it has always been, a challenge no matter what.

Final Expression of Gratitude

The evaluator was hugely impressed with so many of the elements of the process of this evaluation, that it is only fair to make note of them. First, the fact that the Department of Community Services has undertaken such a rigorously independent and far-reaching review is exceptional in Canada and many other locations. It is all the more impressive that this was done, given the low priority that people with disabilities have had generally in Canada in recent years, and the crushing cynicism about government that provides such an easy "out" for many. *The Department was notably ethically meticulous in both its cooperation with the reviewer, and in its painstaking efforts to ensure that the independence of the review was exactingly observed.* It wholeheartedly, at every turn, supported access of people to the reviewer and provided all information requested promptly and completely. Absolutely no effort was made to influence the review by any officials, even when it would have been quite appropriate for representations concerning their priorities to have been made. If anything, the views of non-Departmental people have had priority over those of the Department.

It was also hugely impressive for the reviewer to witness the outpouring of concern and commitment of so many "ordinary" citizens of Nova Scotia. The depth of their concern for the people served, the state of the system, the future prospects for the Province, and their passion for particular elements all gave the evaluation a kind of momentum and gravity that it may otherwise of lacked if it had been ignored. It is also important to recognize the many hours of work organizations and individuals of all kinds put into meetings, submissions and other organizing efforts.

The strong presence of the voice of people with disabilities of various kinds was impressive, as it shows the kind of "coming of age" of these movements taking their proper role in public life. It is also worth noting the many families and friends of people who also showed their concern and solidarity repeatedly. Were it not for theses countless people the evaluator might never have properly appreciated many matters. Despite their best efforts, there are still likely to be many issues that were not properly reflected in this report. Nevertheless, these many individuals will see signs of their own voices and concerns in these pages and know that their efforts were effective.

We all very much rely on each other in our lives and communities, and can only move ahead when we unite our efforts for a better future. This seems very possible in Nova Scotia, but it will ask of all of us that we find ways to act as one where before we were divided. It is people that are the ultimate movers of this world, and the systems we create are merely the manifestation of the people whose vision and choices they reflect. It seems sensible to be thankful for what these many committed and talented people reveal about what is possible in Nova Scotia, as it is on their shoulders that the future stands.

Executive Summary

An Independent Evaluation Of The Community Based Options System Of The Nova Scotia Department Of Community Services

Background

The Nova Scotia Department of Community Services, in the spring of 2000, commissioned an independent review of its Community Based Options system. Dr. Michael J. Kendrick, an independent international expert in the field, a native of Nova Scotia, and currently resident in Massachusetts, was engaged to conduct the review. This was done in a very public and transparent manner, with numerous opportunities for people to make their concerns and views known. A special effort was made to solicit the input of the many individuals and families who relied on the system, and the community organizations that represented them.

Terms of Reference

The review was given very broad terms of reference to advise the government on, both where Nova Scotia presently stood in regards to its Community Based Options residential system, and how it needed to be developed in the years ahead. This review was distinctive in that it was asked to examine a *whole system* of long term residential care serving approximately 1700 people with physical, intellectual and mental health disabilities.

The Community Based Options System

The CBO system constitutes the core of the support system for residential care in Nova Scotia. It has been the largest growing system of care and has extensively helped, over the past several decades, to reduce the Province's reliance on outdated institutional care. Not included in the review were licensed homes that served the same population, but in other models of community care e.g. large group homes, boarding homes and so forth. The CBO system is distinctive in being a system of "small options", which includes small group homes of three or less people, associate family homes and supervised apartments.

The Strengths Of The CBO System

The review identified many strengths in the CBO system. These included the following;

- It was able to serve a wide range of people with quite challenging needs
- It was managed very economically with little waste

- It had very extensively kept people's homes small and often quite personalized
- It had successfully helped many leave institutions and resettle in the community
- It had proven to provide very dependable support and had never abandoned anyone it had promised to care for
- It had assisted with the community inclusion of the people it supported
- It had largely kept unnecessary bureaucracy out of people's lives
- It had developed an extensive community service provider network
- It had pioneered on a small scale some important mechanisms to respond to individual needs
- It had laid a base for quite a degree of local self-sufficiency for services of this kind
- It had attracted a very large base of community interest, advocacy and potential community involvement

The Nova Scotia CBO system was well within the typical range for systems of this kind elsewhere, and had experience very similar issues and challenges. It was above average in its steadfastness to keep people's homes small and in keeping bureaucratic demands and presence in the homes comparatively low.

The Issues Facing The CBO System

The challenges facing the CBO system are quite typical of these kinds of long term care community residential systems. The issues that have emerged from this evaluation are nevertheless, in some cases, more pronounced than in other jurisdictions due to the lack of investment the CBO system has had for some time now. What follows are the seven major areas the report addressed. At the end of each section are the principal recommendations of the report, as well as the pages of the main report that will help the reader locate them. There are many further observations, suggestions and recommendations contained in the narrative of the main report.

An Acute Need For Renewal, Modernization And Political Priority

The CBO system has fallen well behind the better systems over the 1990's, due to a rather severe depletion of its internal or systems infrastructure that has persisted for well over a decade. This has come about as various governments have neglected the system, and failed to provide for its modernization and renewal. The evaluation particularly highlighted the need to invest in programmatic or service delivery renewal, rather than conventional administrative practice. It emphasized "people related" investments such as the priority including leadership development, education for innovation and quality, advocacy and citizen involvement.

The review recommended an updating of the Act and regulation governing these services, to include provisions for shifting the core emphasis away from the creating of service agency controlled homes, to a stronger role for people with disabilities and their families in participating in shaping the kinds of assistance that would best meet their needs. It also recommended a five-year renewal period, to be guided by a citizen leadership panel, to gradually update the system and to draw the community sector into a stronger sense of purpose and shared direction.

The system very much needs political attention and priority, as the Department of Community Services and its CBO system, is now in such a depleted state, that it lacks sufficient people and financial resources to undue this decline. Of these, the people resources are the most crucial to systems improvement, but these cannot be improved without some financial strengthening. The report outlines an aggressive set of issues related to quality that would form the basis for stimulating improvements.

The effects of the decline are many, and include widespread demoralization, suspicion of the motives of government, an eagerness for new leadership, a worrisome lack of safeguards for very vulnerable people, highly limited access to services, almost a cessation of innovation, no resources for improvement, citizen and family alienation from the system and a great many lost opportunities for Nova Scotians with long term disabilities to have better options i.e. an unnecessary stalling of practical social progress.

The evaluation noted that the CBO system needed a plan for its renewal and recommended that the Province request this of the Department of Community Services. It also recommended that the Citizen Leadership and Renewal Panel focus its attention on the crucial "people development" aspects of renewal and innovation.

Specific Recommendations Concerning Modernization and Political Priority

(1.0) Major Recommendation One: The Province of Nova Scotia Should Authorize The Necessary Modernization and Renewal Of The CBO System 54

(1.1) Subsidiary Recommendation (One) To Major Recommendation One: The Province Of Nova Scotia Should Require Of the Department of Community Services The Development Of A Five Year Renewal Plan For The CBO System As A Basis For Improved Funding 54

(1.2) Subsidiary Recommendation (Two) To Major Recommendation One: The Minister For The Nova Scotia Department of Community Services Should Appoint An Independent Blue Ribbon Citizen Leadership and Renewal Panel To Oversee And Guide The Revitalization Of The System 56

(1.3) Subsidiary Recommendation (Three) To Major Recommendation One: The Leadership and Renewal Panel Should Initiate And Oversee An Ongoing Strategic Leadership, Renewal And Innovation Training/Education Plan 58

(1.4) Subsidiary Recommendation (Four) To Major Recommendation One: The Leadership and Renewal Panel Should Collaborate With Other Jurisdictions To Gradually Establish Or Utilize The Educational Resources Needed To Revitalize The Nova Scotia System 60

(1.5) Subsidiary Recommendation (Five) To Major Recommendation One: The Leadership and Renewal Panel Should Sponsor An Annual Progress and Change Conference For The Field 61

An Emphasis On The CBO System Producing More Individualized Options

The evaluation noted that the bulk of the CBO options still remain group living options, and that these sorts of options are increasingly seen by service users, families and the majority of professionals, as much too restrictive, quasi-institutional, and inadequately individualized in view of the more "personalized" options that are increasingly being developed in the field. It noted that personalized options of this kind have already been developed, often rather innovatively, in Nova Scotia and that this should be built upon.

The evaluation recommended a cluster of technical changes aimed at making the transformation of group living into more flexible and personalized arrangements possible. Of these, several related to the dismantling of the old facility focused residence, classification and service categorization system, and the gradual putting into place of a "core" flexible personal and family supports program that would operate under quite different and updated approaches. This would include more authority and decision-making shared with the service users and their families as well as assistance in working out better living arrangements, a version of flexible individualized funding, more options by way of sharing homes with non-disabled persons, new flexible ways to permit people and their families to contribute their own resources to living arrangements, and considerably less reliance on "fixed" or standardized models of care and support.

The preceding innovations are expected to be quite challenging to implement, and may take five to ten years to become established, depending on the quality of leadership present. It was extensively recognized by the evaluation that individualized solutions also have their own shortcomings that need to be managed. A central task is the re-use of existing recurrent funds, and the gradual movement of these resources from standardized service settings to more flexible and individualized ones. Another key task cited by the evaluation, is that of accelerating the rate at which it becomes possible to offer the people left in Nova Scotia institutions a community placement. Nova Scotia has not proceeded as promptly with this as is practical.

Specific Recommendations Concerning Improvements With Individualized Services

(2.0) Major Recommendation Number Two: The Nova Scotia Department of Community Services Should Gradually Reshape Its CBO Residential System In Order To Make Flexible Personal And Family Supports The Core Modality Of The System 67

(2.1) Subsidiary Recommendation (One) To Major Recommendation Two: The Province of Nova Scotia Should Introduce New Legislation To Supersede And Update The Present Homes For Special Care Act In the Direction Of Fostering More Personalized Support Arrangements 68

(2.2) Subsidiary Recommendation (Two) To Major Recommendation Two: The Service User and Their Supporters Should Be Entrusted On A Delegated Basis With Sufficient Authority To Influence The Character Of The Supports They Receive 70

(2.3) Subsidiary Recommendation (Three) To Major Recommendation Two: The Nova Scotia Department of Community Services Should Revise The Present Residential Service Program Categories 72

(2.4) Subsidiary Recommendation (Four) To Major Recommendation Two: The Present Classification System Should Be Replaced By A Simple Eligibility and Priority System 73

(2.5) Subsidiary Recommendation (Five) To Major Recommendation Two: The Province Should Reconsider And Reverse Its Recent Decision To Move Home Care For Disabled People To The Health Department 74

(2.6) Subsidiary Recommendation (Six) To Major Recommendation Two: The Nova Scotia Department of Community Services Should Permit And Encourage Funds Currently Held In Established Or Fixed Residential Models To Be Used More Flexibly On Behalf Of Individuals 75

(2.7) Subsidiary Recommendation (Seven) To Major Recommendation Two: The Department of Community Services Should Establish A Form of (Elective) Flexible Individualized Funding That Would Permit Services Users

And Their Supporters To Have Substantial Influence On How Resources Devoted To Their Use Are Utilized 78

(2.8) Subsidiary Recommendation (Eight) To Major Recommendation Two: The Department of Community Service Should Ensure That Service Users and Their Supporters, Community Providers and Departmental Personnel Are Provided Ongoing Technical Assistance In Learning How To Optimally Transform Existing Service Models Into Desirable Personalized Support Arrangements 83

(2.9) Subsidiary Recommendation (Nine) To Major Recommendation Two: The Department Of Community Service Should Accelerate Its Efforts To Support The Inclusion Of Persons With Disabilities Within Community Life Who Are Presently In Nova Scotia Residential Institutions 85

(2.10) Subsidiary Recommendation (Ten) To Major Recommendation Two: The Department Of Community Service Should Intensify Its Efforts To Support Home Sharing With Non Disabled Persons 87

(2.11) Subsidiary Recommendation (Eleven) To Major Recommendation Two: The Department Of Community Service Should Intensify Its Efforts To Support The Improved Community Inclusion Of Persons With Disabilities 89

(2.12) Subsidiary Recommendation (Twelve) To Major Recommendation Two: The Department of Community Services Should Explore Ways To Make It Possible For Individuals and Families To Share In The Financing Of Some Elements of Services 91

A Move Toward Strengthening The Role and Influence of Service Recipients and Families

The CBO system and its contemporaries worldwide have been a large and unusually successful step towards escaping a past, in which people with disabilities were "custodialized" and excluded from society. Nevertheless, a good deal of paternalism still exists which stands in the way of letting people with disabilities and their families have the level of control of their lives that is due to them. The evaluation has recommended a variety of practical innovations that would greatly assist in this relative to their personal influence on service delivery.

These include a new starting point for obtaining and designing services that would enable the person and their allies to devise arrangements "from the beginning" or "bottom up", without having to enter into pre-existing services. This would be dependent on the Department authorizing service users and families to have the benefit of some key "participation rights" regarding their ability to negotiate with the Department and service providers. These individual level options would be supplemented by the further option of the service user and families establishing "mini" projects of their own, that they could guide, govern and manage as might be needed.

The present CBO system has a measure of formal citizen oversight through the boards of the private providers. The public system has no such empowered citizen oversight and the evaluation recommended that this be corrected through the establishment of variably constructed regional community governance boards. Their mission would be to oversee and guide the local system, to make it more transparent, responsive to needs, decentralized at the level of operation and priorities, and pro-active in regards to partnerships with the community.

Specific Recommendations Concerning Strengthening Service User, Family and Citizen Influence

(3.0) Major Recommendation Three: The Department of Community Services Should Update Its CBO System In Regards To Service User, Family and Community Participation And Partnership 106

(3.1) Subsidiary Recommendation (One) To Major Recommendation Three: The Department Of Community Service Should Develop Specific Regulations And Policy To Assure Strong Service User and Family Participation Rights 106

(3.2) Subsidiary Recommendation (Two) To Major Recommendation Three: The Department of Community Service Should Explore The Establishment Of Mandated Regional Community Governance Mechanisms 108

(3.3) Subsidiary Recommendation (Three) To Major Recommendation Three: The Department of Community Services Should Establish A New Mechanism That Would Permit Service User and Family Governed Mini-Projects To Be Established 109

Stimulation Of Needed Innovation

The CBO system has reached a very low point in generating innovations though independent individuals and groups have done much better. The evaluation has recommended a wide variety of measures that would facilitate needed innovation. These include the recruitment of innovators, the development of targets for innovation, better recognition of innovations, closer attention to what service users say they need, flexibility for individuals and agencies to experiment, educating and updating the field, increased exposure and contact with innovators, scholarships and stipends for studying innovations, training and technical assistance for innovation and so forth.

The evaluation particularly emphasized the expansion of contact between people in Nova Scotia and innovators in the broad field, thereby arguing for a greater emphasis on looking outward and rapidly applying the potential benefits to Nova Scotia. It emphasized that many of the local innovators could be encouraged through the establishing a tradition of "bottom up" experimentation. It also emphasized that service expansion be into innovative arenas so as to embed this goal of innovation more strategically into service operation.

Specific Recommendations Concerning Increasing Innovation In The CBO System

(4.0) Major Recommendation (Four): The Department of Community Services Should Help Establish The Conditions That Will Increase The Likelihood of Innovation And The Emergence Of Innovators 120

(4.1) Major Subsidiary Recommendation (One): Any Service Expansion For the Foreseeable Future Should Be Undertaken Principally Within Innovative Service Personalized Support Arrangements 123

(4.2) Major Subsidiary Recommendation (Two): The CBO System (Overall) Should Expand Its Degree Of Contact With Innovators Within And Outside Nova Scotia 124

The Improvement Of Safeguards

The population being served by the CBO system includes some of the more dependent and vulnerable people in Nova Scotia. These are also people that, as a group, face much higher rates of mistreatment and devaluation than do most of their fellow citizens. The evaluation saw an important need to improve the safeguards these people have available to them. It recommended that the standing and role of the service user and their families as advocates for the person need to be recognized and strengthened. It also recommended that, beginning with the most vulnerable, there should be established a way to secure independent advocates for people.

It also recommended that there be established, at the regional level, various models of independent citizen monitoring of services. It also recommended a new mechanism that would permit, at the level of individuals, a negotiating process to establish highly individualized safeguards as it related to a given person's concerns and vulnerabilities. In regards to persons who posed the most worrisome concerns, it was recommended that a specific mechanism be developed to identify these persons and their exceptional vulnerabilities, and ensure that there was no ambiguity as to who needed to address these matters.

The evaluation saw a need to have the person served, and their family, play a more prominent role in deciding if a situation was acceptable, and what could be done to make it so. It was also recommended that special recognition be given to individuals whose religious, cultural, ethnic, dietary, linguistic, and lifestyle preferences were properly respected. This was extended to include persons whose preference was some measure of reclusive living, those who wished to live in intentional communities and other persons whose numbers very small minorities.

Specific Recommendations Concerning Intentional Safeguards

(5.0) Major Recommendation (Five): The Nova Scotia Department Of Community Services Should Arrange To Provide Individuals That Need It With Independent Advocacy, Representation And Possibly Other Intentional Safeguards To Assure Their Well-Being 136

(5.1) Subsidiary Recommendation (One) To Major Recommendation Five: The Nova Scotia Department Of Community Services Should Officially Recognize and Give Advocacy Standing To Service Users, Their Families And Allies 137

(5.2) Subsidiary Recommendation (Two) To Major Recommendation Five: The Department of Community Services Should Establish, At The Regional Level, Mechanism(s) For The Independent Community Monitoring Of The Circumstances Of People Supported By The CBO System 138

(5.3) Subsidiary Recommendation (Three) To Major Recommendation Five: The Department Of Community Services Should Establish A Mechanism So That Crucial Personalized Intentional Safeguards Can Be Negotiated And Enacted For And By Individuals Who May Need These 140

(5.4) Subsidiary Recommendation (Four) To Major Recommendation Five: The Department Of Community Services Should Install A Specific Safeguard To Resolve The Ambiguity Of Who Is Directly Responsible In The Case Of Individuals Who Need Supervision To Prevent Them Being Harmed Or Harming Others 142

(5.5) Subsidiary Recommendation (Five) To Major Recommendation Five: The Department Of Community Service Should Recognize The Validity Of Individuals Preferring To Voluntarily Live In Intentional Communities, Seek Lives Of Relative Reclusiveness Or Live In Households With Distinct Cultural, Religious Or Ethnic Identities 144

The Departmental Interim Guidelines For The CBO System

The evaluation was asked to examine these. It recommended a new approach to licensing, which shifted licensing from a focus on the homes to a pre-qualifying license to operate for the service providers involved in supporting people. This proposed new system would thereby have a single licensing program for residential services, and eliminate the CBO program from its present unlicensed status. The determination of the quality of service being offered was recommended to become a regular part of the service contracting process.

The present "Interim Guidelines" were recommended to be replaced by what has been called the "Consensus Guidelines", produced collaboratively with the community, but never adopted. An updated version of these was recommended. These were to be to be left in place, until a new regulatory regime was installed that reflected the changes envisioned by this report. To better assist in the determination of what quality of service ought to be, a set of service user related quality outcomes were to be developed.

Specific Recommendations Concerning The Interim Standards

(6.0) Recommendation One: The Present System To License Homes Should Be Replaced With A System To License Service Providers 147

(6.1) Recommendation Two: The Specification And Monitoring Of The Quality Of Supports Should Be Largely Taken Up As Part Of Service Contracting Rather Than Licensing 150

(6.2) Recommendation Three: An Updated Version Of The Consensus Guidelines Should Serve As The Interim Guidelines Until The New Proposed Licensing System Is Put Into Place 152

(6.3) Recommendation Four: There Should Be Developed A Set Of Desirable Outcomes For Service Users As A Key Ingredient Of The Proposed Quality Contracting System 152

Important Unresolved Matters Relative To Persons With Mental Health Disorders

The community support of persons with mental health disabilities has suffered for many years from falling between the jurisdiction of the Department of Community Services and the Department of Health. This "split" jurisdiction, has essentially ensured that these persons are deprived of a "seamless" or singly managed system of care and support. The evaluation recommended that this be corrected by a political decision, taken promptly, to establish a single mental health community support system. It recommended, as a preliminary step an independent review of what new mechanism would best accomplish this, and the compilation of data needed to assist with this decision.

The evaluation noted the specific financial issues involved in the departure of persons from CBO arrangements into psychiatric in-patient care, and the placement of persons from in-patient care back to the community. It recommended several new financing arrangements that would essentially establish a transitional period of joint Health and Community Services funding to ensure that the bridging of these two systems was uninterrupted at the level of the person served.

Also, in recognition of the possibility that some individuals with mental health disorders may get lost between these systems, in regards to a seamless handover of responsibility and supervision, a specific new mechanism was proposed to eliminate this likelihood. It was also noted that many persons with long-term mental health conditions are extremely poor and may possibly be at risk of having no alternative but to take poor housing. It was recommended that in these instances a rental subsidy be made available to diminish this likelihood.

Specific Recommendations Related To The Mental Health Component Of The CBO System

(7.0) Major Recommendation (Seven): The Department of Community Services And The Department of Health Should Resolve The Creation Of A Single Community System To Serve Persons With Mental Disorders Within Two Years 158

(7.1) Subsidiary Recommendation (One) To Major Recommendation Seven: The Nova Scotia Department of Community Services And The Department of Health Should Establish A Mandated Joint Working Party To Prepare The Background Data Needed To Proceed With Recommendation Seven........ 159

(7.2) Subsidiary Recommendation (Two) To Major Recommendation Seven: The Department of Community Services And The Department of Health Need To Restructure The Fiscal Incentives Regarding Community Placement........ 159

(7.3) Subsidiary Recommendation (Three) For Major Recommendation Seven: There Should Be Established Between The Department Of Community Services A Joint Mechanism For Ensuring That High Risk Individuals Are Properly Identified And Safeguarded 161

(7.4) Subsidiary Recommendation (Four) For Major Recommendation Seven: The Department of Community Services Should Establish A Rental Subsidy Program That Reduces The Likelihood Of Its CBO Service Users Having To Use Poor Housing 162

The Overall Priority Of Recommendations

The evaluation recognized the rather long-term nature of many of the remedies it proposed, and the overarching necessity for unusually competent leadership, from many quarters, in order to progress these. It also recognized that this must begin with some significant political leadership as a precipitating catalyst. This would be facilitated by the adoption in principle of the general directions of the report.

From amongst the many recommendations made, the evaluation repeatedly emphasized the focus on renewal and the "people development" component of this. This was followed by an emphasis on beginning the creation of the mechanisms needed for individualization, innovative experiments and service user empowerment. The report urged prompt action to ensure that the most vulnerable had access to independent advocacy.

Lastly, the evaluation report urged the taking of a decision to resolve the "split jurisdiction" question as it affected persons with mental health disabilities. While the evaluation favored an expansion of resources to the CBO system, as a part of it regaining political priority, it urged on several occasions, that new resources not be diverted into service expansion of the present system. Rather, the evaluation was exceedingly clear that the priority should be on improving the CBO system by modernizing it.

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